

**Analysis of the Stakeholder Derived Conceptual Models & Exploration of Lung Cancer
Screening Barriers in a Medically Underserved Area**

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Computed Tomography (LDCT), screening barriers, attitude, knowledge

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ABSTRACT

The number of new cases of lung and bronchus cancer was 55.8 per 100,000 men and women per year.¹ The number of deaths was 44.7 per 100,000 men and women per year.² These rates are age-adjusted and based on 2010-2014 cases and deaths. Each year, more people die of lung cancer than of colon, breast, and prostate cancers combined.³ The knowledge that lung cancer can be successfully treated if caught early has driven a decades-long search to find an accurate and reliable screening test. National Cancer Institute's National Lung Screening Trial (NLST) found that annual screening with Low-Dose CT (LDCT) for asymptomatic patients aged 55 to 74, with a smoking history of at least 30 pack-years, and smokers who quit less than 15 years ago, had a 20% reduction in risk of death from lung cancer.⁴ Findings of this trial resulted in that LDCT becoming the gold standard of screening for lung cancer.^{5,6,7} The SEED method is a community-engaged research approach to develop conceptual models and generate patient-centered research questions. This method has been used to engage community stakeholders of Martinsville, Virginia to develop conceptual models of the factors contributing to lung cancer outcomes. In the first manuscript of this dissertation, these models which were produced by 3 different groups of stakeholders have been examined closely to explore the complexity, similarities, and differences. The models were used to produce a research agenda on the topic of factors impacting lung cancer outcomes for future researchers. A literature review was conducted by the study team on the final research agenda. The goal of this literature review was to avoid duplication of research and to focus future research on the identified gaps.

The knowledge and attitudes of the health care providers and patients about lung cancer screening and the barriers in the uptake of LDCT were identified as a research gap. The design of the Martinsville lung cancer study described in the second manuscript of this dissertation responds to this identified research gap. These studies and their results shed light on the factors that impact lung cancer outcomes using a community based participatory approach.

Key Words:

Stakeholder, Conceptual Model, Factor, Category, Linkage, Perspective, Low-Dose Computed Tomography (LDCT), Health care provider, lung cancer, screening barriers, attitude, knowledge.

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Analysis of the Stakeholder Derived Conceptual Models & Exploration of Lung Cancer Screening Barriers in a Medically Underserved Area

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GENERAL AUDIENCE ABSTRACT

Each year, more people die of lung cancer than of colon, breast, and prostate cancers combined. Many researchers are studying to find an accurate and reliable screening test for lung cancer by testing the knowledge that if lung cancer can be successfully treated if caught early. One study that was conducted by National Cancer Institute found that annual screening with Low-Dose CT (LDCT) for patients who are 55 to 74, without any symptoms, with a smoking history of at least 30 pack-years, and smokers who quit less than 15 years ago, lowered their risk of dying from lung cancer. Findings of this study resulted in that Low-Dose CT becoming the best screening test for lung cancer. The SEED method is a research method to create conceptual models and produce research questions based on the direct feedback from patients and other stakeholders. This method has been used to engage community stakeholders of Martinsville, Virginia to develop conceptual models of the factors that impact the lung cancer outcomes in this area. In the first manuscript of this dissertation, these models have been examined closely to find their similarities and differences and to find out how complex they are. After generating the research questions by using these models, related studies were reviewed by the study team to find the gap of information on this topic.

This review revealed that there is a gap of information in the knowledge and attitudes of the health care providers and patients about lung cancer screening and the barriers in using the Low-Dose CT. The design of the Martinsville lung cancer study described in the second manuscript of this dissertation is an answer to this gap of information.

Dedication

I dedicate this dissertation to:

My father and my mother who have made many sacrifices in the life to ensure their children could pursue higher education and accomplish their goals. My father taught me to be strong and never give up in life and my mother taught me to love without any condition.

My awesome husband, Mohammad who has supported me unconditionally and provided me with the love and encouragement in the life's ups and downs. He has set a true example of determination and hard work while being compassionate & caring.

My two beautiful children, Mohsen & Sara for being a source of love and comfort and making me stronger, better and more fulfilled than I could have ever imagined in life.

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The type of the research I have conducted during my doctorate program as well as my employments I have had in each summer, were mostly “public health” related which I truly enjoy, and I am passionate about it. The foundation of the public health and the required skills for that come from the Public Health program (department of population health sciences) at Virginia Tech. I have finished medical school and worked as a family physician for some time. Being a family doctor opened my eyes to the importance of the prevention and preventive medicine. In my search to fulfill my interest on that field, I had a pleasure to meet Dr. Kerry Redican who later became my mentor and advisor in the public health program at Virginia Tech. Dr. Redican introduced me to the principles of the public health and during my practicum and capstone projects taught me how to conduct a community-based research. Dr. Redican has been very helpful during all the years I have been at VT and later he continued his support as a committee member for my PhD program. Dr. Kathy Hosig and Dr. Susan W. Marmagas were my other academic mentors as well as good friends in the public health program who deepened my love for the public health through their class projects, courses or professional workshops.

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List of Abbreviations

| List of abbreviations used in this dissertation | | |
|---|---------------------|--|
| # | <u>Abbreviation</u> | <u>Description</u> |
| 1 | LDCT | Low-Dose Computed Tomography |
| 2 | SEED | Stakeholder Engagement in quEstion Development |
| 3 | HBF | Health Behavior Framework |
| 4 | SBM | Society for Behavioral Medicine |
| 5 | I-ELCAP | International Early Lung Cancer Action Project |
| 6 | NLST | National Lung Screening Trial |
| 7 | CDC | Center for Disease Control and Prevention |
| 8 | TG-HP | Topic Group-Health care providers |
| 9 | TG-SC | Topic Group-Survivors & Caregivers |
| 10 | TG-AI | Topic Group-Access Influencers |
| 11 | SCAN participants | Stakeholder ConsultANts |
| 12 | USPSTF | US Preventive Services Task Force |
| 13 | NCCN | National Comprehensive Cancer Network |
| 14 | B | Barrier (Lung Cancer Screening) |
| 15 | F | Facilitator (Lung Cancer Screening) |

Introduction

A community-engaged project evaluating the cancer resources and needs in Martinsville/Henry County, Virginia has been ongoing since 2013. The research reported in this dissertation was conducted within the context of those activities and is in two parts. The first part does an in-depth analysis of the process of stakeholder engagement in development of the conceptual models around lung cancer outcome disparity in the community. The second part is a new research study designed based on the identified research gap to evaluate the knowledge and attitudes of health care providers and patients toward lung cancer screening and the existing barriers to lung cancer screening from their perspective.

Stakeholders from the Martinsville community were recruited to form a core community research team and 3 Topic Groups (Healthcare Providers/TG-HP, Survivors and Caregivers/TG-SC, and Access Influencers/TG-AI). These three topic groups created concept models of the factors affecting lung cancer outcomes. We explore the complexity, similarities, and differences of the conceptual models developed by these diverse community stakeholders which is the focus of the first manuscript in this dissertation. After creation of the concept models, stakeholders produced a research agenda on the topic of lung cancer.

A comprehensive literature review was conducted for the research agenda to avoid duplication of the research on these topics. Based on the identified research gap, a lung cancer study was designed and conducted in Martinsville to answer the following research questions: (1) What are the differences and similarities between barriers to lung cancer screening from the perspective of the health care providers and patients?, and (2) What are the facilitators to lung cancer screening among patients who received the screening on time after a physician's recommendation and what

are the screening barriers for those who received the screening late after a physician recommendation?

We hypothesized that health care providers and patients have similar as well as distinct barriers to lung cancer screening. We also hypothesized that patients who received the screening on a timely manner after a physicians' recommendation, have specific facilitators in helping them to get the screening and patients who got the screening late, have specific barriers that prevented them from getting the screening on time.

We evaluated 1) referring health care providers' knowledge and attitudes toward LDCT, and their perspectives on patients' barriers to compliance with lung cancer screening, 2) knowledge, attitudes and beliefs of patients toward lung cancer screening, 3) identify screening facilitators among early compliers and screening barriers among late compliers, and 4) compare the lung cancer screening barriers from the perspective of health care providers and patients.

In the second manuscript, the knowledge and attitude of the patients and health care providers toward lung cancer screening and the existing barriers in uptake of the Low-dose computed tomography (LDCT) among these two populations have been reported.

Our overall focus in these studies is to engage community members in different ways to collaboratively work together to identify the factors that affect lung cancer outcomes which will lead to creation of different methods to improve lung cancer outcome in this area. The research methodology that is described in this dissertation is based on the lessons learned from the community which is the principle of the population health approach to improve disease outcomes. More information about these studies are provided in the following chapters.

CHAPTER 1

Title: Analysis of the Stakeholder Derived Conceptual Models

1.1 ABSTRACT

Background:

The SEED method is a community-engaged research approach to engage community stakeholders to develop conceptual models and generate patient centered research questions. By engaging a range of stakeholders with diverse experiences in 3 Topic Groups (TG), 6 Focus groups, and 10 key informant interviews, we dig deeper into stakeholders' understanding and perspective of the factors affecting lung cancer outcomes in Martinsville, Virginia through concept modeling of the factors affecting lung cancer.

Methods:

Stakeholders from the community were recruited to form a core community research team and 3 Topic Groups (Healthcare Providers/TG-HP, Survivors and Caregivers/TG-SC, and Access Influencers/TG-AI). Focus groups (20 participants) and (10) key informant interviews were conducted to inform the topic groups. Each topic group created a concept model of the factors affecting lung cancer outcomes. Factors were categorized, and the final models were compared for complexity; type, number and position of categories/factors in each model, and overall perspective.

Results:

TG-HP produced the most complex model based on the number of factors, categories, and linkages within the model. TG-HP had 21 categories with 55 factors, TG-SC had 19 categories with 38 factors, and TG-AI had 15 categories with 37 factors. TG-HP had the greatest number of linkages between factors (TG-HP =68, TG-SC=48, TG-AI=31).

Twelve categories were common among all three groups, 4 categories (Behavior, Healthcare access, Personal & family characteristics and Social Values) were common among 2 TGs and 5 categories were unique to only 1 TG. Common categories in the 3 models, included both similar and different factors which represented the diverse perspective and experience of the topic groups. Five of the connections in the TG-HP model were bidirectional, 3 connections in the TG-AI were bidirectional and TG-SC had zero bidirectional connections.

TG-HP had 5 direct connections from categories to the lung cancer outcomes, TG-SC had 6 direct connections while TG-AI had only 4 direct connections. A total of 90 factors were identified between the three groups. Among these; 64 were unique to one topic group, and 26 were found in 2 or more of the models.

The variance in factors, categories, and their position gave a unique perspective to each model. TG-HP emphasized health care factors and positioned them closest to lung cancer outcomes, TG-SC highlighted factors within a patient's control such as "Behavior" and placed them closest to lung cancer outcomes, while TG-AI emphasized more on the macro-environment.

Conclusion:

The SEED Method effectively engaged key community stakeholders with diverse viewpoints in analysis of a community relevant cancer issue through conceptual modeling. TG-HP produced

the most complex model based on the number of factors, categories, and linkages within the model. Also, different emphases of the topic groups lead to a broader range of knowledge produced from the design of the concept models and enriched the final product. By engaging stakeholders in the research process, we potentially improve the process of the research translation to address the health issue of focus in different populations.

Key Words: Lung cancer, Stakeholder, Conceptual Model, Factor, Category, Linkage, Perspective, Risk factors.

TG-HP: Health care Providers

TG-SC: Survivors and Caregivers

TG-AI: Access Influencers

1.2 INTRODUCTION

Community-engaged research is a framework or approach for conducting research, not a methodology in and of itself. It is characterized by the principles that guide the research and the relationships between the communities and academic researchers. Community-engaged research requires partnership development, cooperation and negotiation, and commitment to addressing local health issues.⁸ This type of research has the potential to prepare stakeholders to successfully collaborate on projects that may be more scientific or technical in nature. Health research organizations and funding agencies have the critical responsibility of deciding where to allocate limited research dollars. Therefore, these organizations and the academic research community increasingly seeks to involve patients and other stakeholders in health research due to a combination of political mandate, accountability and a desire for better quality research, including increased validity, relevance, acceptance and sustainability.⁹ These efforts help to increasingly engage various stakeholders as well as end users of health research throughout the research process.

Community engagement in research works best where it is an ongoing cumulative process enabling relationships and trust to build and strengthen over time. Community or voluntary groups may want to participate at a range of levels – from providing advice to co-designing the process and from undertaking some aspects of the engagement to delivering projects to meet some of the outcomes.¹⁰ Community stakeholders can participate in a variety of ways, and at different levels of influence. Providing information, consultation and active participation are levels of stakeholder engagement along a community engagement continuum, with increasing levels of engagement and influence towards the ‘active participation’ end of the spectrum (Figure 1.1).¹¹

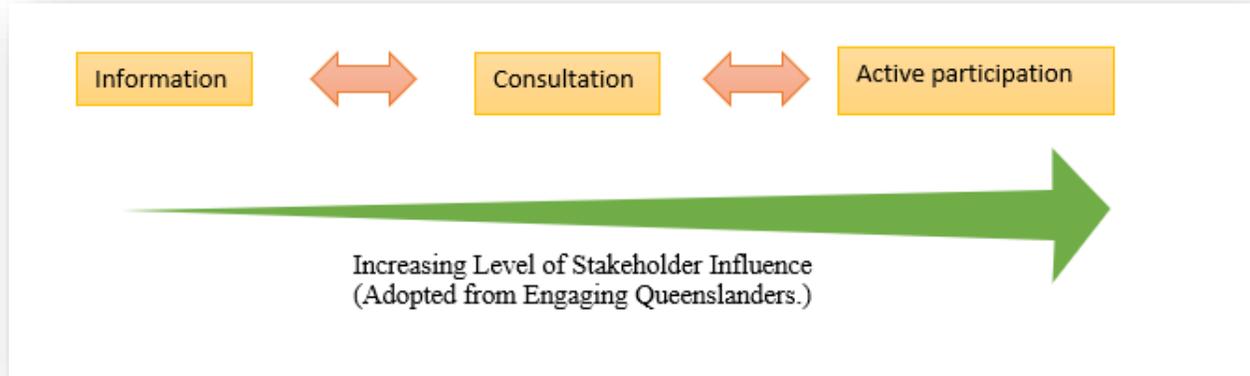


Figure 1.1: Increasing Level of Stakeholder Influence (4)

Engagement of those directly impacted by the health issues or end users of the health research in conceptual modeling and the identification and prioritization of research topics has the potential to advance the inclusion of their unique experiential understanding and underlying values, and ensures that the concerns and needs of stakeholders are reflected in the selected research priorities^{12, 13, 14} The method of stakeholder involvement in the research process provides opportunities for research that is more valid, relevant, accepted, and sustainable.¹⁵

A review of the best practices, processes, and methods of stakeholder engagement in conceptual modeling of the related health topic and research topic development identified four types of engagement: 1) minimal engagement, 2) consultations, 3) collaborations, and 4) publicly controlled engagement.¹⁶ Combining methods for consultation with a process of collaboration has provided the best outcomes. Community stakeholders in Martinsville, Virginia were, engaged in a project to develop conceptual models and research questions and then prioritize research questions related to factors that affect lung cancer outcomes in this area.

Health Topic: Lung Cancer

Lung cancer is the leading cause of cancer death and the second most common cancer among both men and women in the United States.¹⁷ The national age-adjusted death rate is 44.7 deaths per 100,000, compared to 45.5 in Virginia, and 73.1 in Martinsville, Virginia.¹⁸ Despite advances in lung cancer treatment, the 5-year survival rate remains very low at only 18.1%.¹⁹ In 2014, there were an estimated 527,228 people living with lung and bronchus cancer in the United States.¹⁹ The costs in morbidity, mortality, and personal and collective healthcare costs are significant. Nearly 28.0 percent of lung cancer-related hospitalizations (149,900 stays) were principally for lung cancer and totaled \$2.1 billion in hospital costs.²⁰ The number of stays principally for lung cancer has remained relatively stable since 1995, while hospitalizations with lung cancer as secondary diagnosis increased 15 percent during this time. Overall, the total number of lung cancer-related hospitalizations has increased 10 percent since 1995, ranging from 475,600 stays in 1999 to a high of 542,200 stays in 2005.¹³

Early detection doubles a person's chance of survival.²¹ Several observational studies have shown that low-dose helical CT of the lung detects more nodules and lung cancers, including early-stage cancers, than does chest radiography.²² The landmark National Lung Screening Trial (NLST) published in 2011 reported that annual computed tomography lung screening reduces lung cancer-specific mortality by at least 20% in individuals at high risk for lung cancer.²³

Low dose computed tomography (CT) is now recommended for people who are considered high risk for lung cancer and is covered by Medicare and other private insurers.^{24,25} Relative risk and mortality rates for lung cancer vary by race and socioeconomic status (SES), among other factors. Smoking is by far the greatest contributor to lung cancer, attributable for 90% of lung cancer cases.²⁶ Many lung cancer risk factors have been identified, but active cigarette smoking

is the predominant cause of lung cancer and the principal marker of both high-risk populations and high-risk individuals.²⁷

African Americans have higher overall cancer incidence and mortality rates, with significantly higher death rates for lung cancer.²⁸ Men and women with less than a high school education had elevated lung cancer risk relative to their college educated counterparts. Those with family annual incomes less than \$12,500 had incidence rates that were more than 1.7 times the lung cancer incidence rate of those with incomes \$50,000 or higher. This means that lower SES groups have higher lung cancer incidence and mortality rates.^{29, 30}

The knowledge that lung cancer can be successfully treated if caught early; has driven a decades-long search to find an accurate and reliable screening test. Despite the recent public policies establishing coverage for lung cancer screening among high-risk populations, lung cancer screening awareness, access, and utilization remain low, particularly among underserved populations.³¹ At-risk, low SES individuals are less likely to get screened compared to higher SES individuals.³² Among modifiable risk factors for lung cancer, smoking and secondhand smoke exposure are by far the most significant, causing 90% of all lung cancer cases.^{15, 16} The prevalence of tobacco use is higher among populations of lower SES, which may be an important cause of disparities in lung cancer death rates.^{33, 34} Lung cancer disparities involve complex interconnected influences of the living and working environment, behaviors, sociocultural factors, and biology of individuals.³⁵

What is SEED method?

There is a need to engage the public in research to increase accountability, relevancy and transparency while generating new insights. Currently, selection of research topics for funding is

the responsibility of the researchers or sponsors alone. Efforts to include stakeholders are hampered by lack of willingness or understanding on the part of both researchers and stakeholders and lack of methodological standards. Few frameworks have been developed for collaborative generation of research questions.

The SEED (**S**takeholder **E**ngagement in **qu**Estion **D**evelopment) method is a combination (collaborative/consultative) engagement model that provides meaningful participation from patients and other stakeholders in the development of concept models predicting health outcomes and development and prioritization of research questions.³⁶ The SEED method is a community-engaged research approach to generate patient centered research questions using concept models developed by stakeholders (Figure 2). We used the SEED method to collect the information from diverse stakeholders consisting of 3 Topic Groups (TG), 6 Focus groups, and 10 key informant interviews which resulted in gaining valuable knowledge of the factors affecting lung cancer outcomes in Martinsville, Virginia.

1.3 METHODS

The SEED method employs a wide range of qualitative methods within a participatory framework: qualitative interviewing; focus groups; structured group participation to identify causal factors related to a health outcome, developing conceptual models, and prioritizing research questions; and a mixed methods evaluation of study processes and outcomes.

By engaging diverse stakeholder experiences through Topic Groups (TG), focus groups and key informant interviews (Figure 2) in facilitated exercises based on community based participatory research (CBPR) principals, we gathered information from various community stakeholders in the topic of lung cancer outcomes. Therefore, this research methodology combines collaborative,

participatory and consultative engagement to provide meaningful participation from diverse community stakeholders.

In this methodology (presented in figure 2), stakeholders participate through three different modes of engagement. The project consisted of 4 major community groups and an Administrative Research Team with the role of overseeing the successful implementation of the method (located at Virginia Tech) as follows;

1. The first group was a community research team which was identified by the administrative research team and hired by Virginia Tech. They had the highest level of engagement, a multidisciplinary partnership composed of stakeholders and researchers to collaboratively lead the research process, identify stakeholders, and analyze the results. This community research team met weekly in Martinsville and led different phases of the SEED project.
2. The second level of engagement was Topic Groups. Three Topic Groups were identified and organized by the community research team based on their affiliation and knowledge about lung cancer (Healthcare Provider TG-HP, Survivors & Caregivers, TG-SC, and Access Influencers, TG-AI). They attended a total of 7 meetings that were held in the Martinsville Memorial Hospital.
3. The third level of engagement was through Focus groups. Focus Group participants were identified by each TG and were conducted with collaboration of the community research team and VT administrative research team. Every topic group identified 2 focus groups (Total 6 focus groups).

4. Finally, the last level of engagement was key informants which were identified by each TG. Each topic group identified a maximum of 4 key informants (12 key informants in total). Key informants were involved only for the duration of one interview. Key informant interviews were conducted by the community research team, but information gathered from them were analyzed by the administrative research team to disseminate to the designated topic group. Topic groups used this information to develop the conceptual model and finally design the research questions.

The community research team had a “Collaborative” role, Topic groups had a “Participatory” role and SCAN participants (Stakeholder ConsultANts) had a “Consultative” role in this project. These different modes of engagement made unique contributions to the project, while working together interactively. (Figure 1.2)

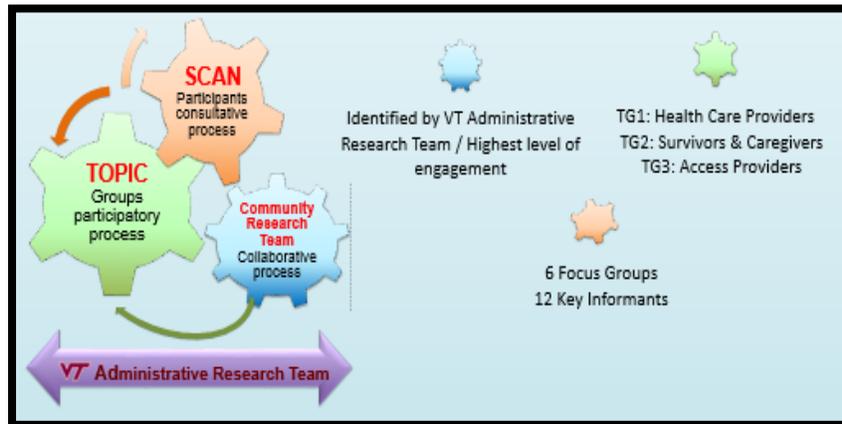


Figure 1.2: Levels of Stakeholder Engagement in the SEED Method

Process of identifying the community research team & their role

Fliers and recruitment materials to identify the community research team were developed by the administrative team and various recruitment strategies were used. These strategies included posting fliers in public places (e.g. public library, hospital, college, etc.), direct communication with some local individuals, and a newspaper advertisement. The target of this recruitment process were residents of Martinsville and Henry County who are older than 18 years old with an interest to work collaboratively with Virginia Tech researchers on the topic of lung cancer outcomes.

Potential participants were asked to have a time commitment of about 6 hours per week for the duration of the project (10 months). All participants received an hourly stipend for the duration of the project. Eleven adults were recruited by the administrative team and participated over the course of the project as members of the community research team.

They had the highest level of engagement, a multidisciplinary partnership composed of stakeholders and researchers to collaboratively lead the research process, identify other stakeholders, and finally analyze the results.

Members of the community research team played an important role in collaborating on research that is responsive to community stakeholder needs and promotes shared responsibility, co-learning and other key principles of participatory research.

Process of Identifying Stakeholders

The community research team went through a facilitated process to identify and recruit topic group participants and then help the topic groups to identify and recruit their SCAN participants (focus groups and key informants). The facilitated process ensures that a representative group of

people who will bring a variety of perspectives to the health issue will be selected. After recruiting and forming 3 Topic groups, a similar process was conducted by each of the topic groups with the help of the community research team, to identify the SCAN participants for interviews and focus groups.

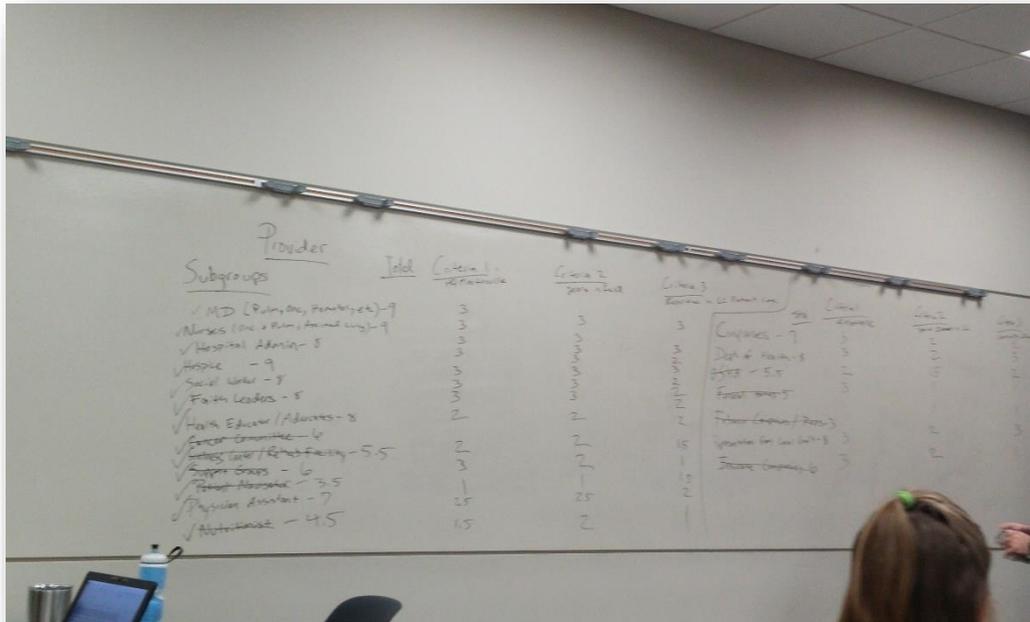
Facilitated Process description

The facilitated process for selecting Topic groups has been explained in detail previously (Zimmerman et. al. ³⁷). Briefly, the purpose of the facilitated process was to identify diverse stakeholder participants based on their demographic, social, and other health related criteria. The community research team went through a process of brainstorming different sub-groups affected by the health topic. In general, sub-groups considered include patients and service providers at a minimum. They then identify and select criteria that will be used when ranking the various sub-groups in order of importance. A voting system determines the priority sub-groups and the final selection is made. Three Topic groups are selected. The last step is to decide where individuals for the Topic Groups can be recruited (Figure 1.3). This figure summarizes the steps that the community research team followed to identify and form the 3 topic groups.



Figure 1.3: Process of Identifying Stakeholders

Please refer to “Matrix and Facilitated guide” in the Appendix for more information about this process, sub-groups and how consensus was reached. Picture 1 shows the process of brainstorming, how the sub-groups were developed and how the consensus was reached in confirming the final sub groups.



Picture 1: Process of selecting subgroups

Choosing composition of the TOPIC Groups

Based on the SEED method protocol, the research team was limited to have a total of three stakeholder TOPIC groups – at least 1 of which must be service providers. Therefore, they could have up to 2 groups of the patient or community member groups of their choice. Throughout this process, the administrative research team directed the group not to choose a narrow criterion, because it makes finding participants more difficult.

On the other hand, they also should not rule out groups because of issues such as age, literacy, or how busy they are (e.g., MDs). The research team recruited participants using fliers in healthcare organizations, non-profit organizations assisting with cancer care, targeted areas that provide cancer care and word of mouth. Among the nineteen participants, there were 15 Females and 4 males (11 white, 7 black, 1 Hispanic). All participants received a stipend for their attendance at a

total of seven meetings. This method was used to ensure that topic group members could provide useful information in the process of developing the concept models and final research questions based on their experience and unique perspective.

The final topic groups were categorized according to their subgroups. (such as patients or cancer survivors in the “Survivors & Caregivers” (SC-TG) group, OR different types of health care providers in the “Health Care Providers” (TG-HP) group.

TOPIC group activities / Designing conceptual models

Topic groups had the responsibility for developing the concept models and research questions. They were involved in a total of 7 meetings, at which they talked at length about their experience with lung cancer and reviewed information about lung cancer provided by the community research team and solicited from SCAN participants. Each TOPIC group developed a conceptual model diagramming the factors that influence lung cancer outcomes based on their own experience, and then created research questions that were important to them.

Each TOPIC group brought their unique perspective of the health topic (here, lung cancer) to the table, and both their conceptual models and research questions reflected this unique perspective. After forming the topic groups, each topic group went through a facilitated process to develop their unique concept model based on the information gathered from their focus groups and key informant interviews. This process is explained below.

A. Review data gathered from the focus groups and interviews

Topic group members were provided with transcript summaries from the focus groups and interviews and engaged in group discussions of the issues that emerged. This was not intended as a formal process of qualitative analysis or coding, but rather it was a way for topic group

members to review and reflect on the themes, issues and concerns of others before embarking on the conceptual model building and question development exercises, allowing them to reflect on their experiences in the context of others. After reviewing data gathered from conducting the focus groups and key informant interviews, topic group members discussed and summarized the findings.

Before starting to develop the actual conceptual models, a training session was conducted by the administrative team with the topic group and research team members, teaching them the conceptual modeling progression (training script is available in the appendix). It was explained to the members that these diagrams are pictures we can use to help us organize information and show cause and effect relationships. Then they were asked to think about an example of “Buying a car” and the factors affecting this decision:

- What else influences whether someone will buy a car?
- Why might someone choose to buy a car?
- Who might be in the market to buy a new car?

The goal of this training session was to help the members to map out the reasons people generally make decisions, or generally do something, such as buy a car.

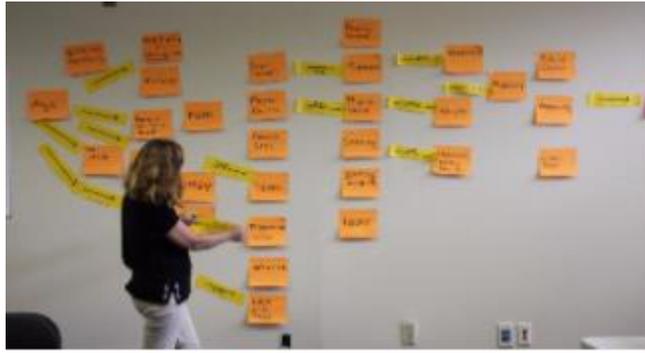
Each topic group worked as a team through a facilitated process (that was conducted by members of the administrative team) to develop their unique conceptual model that listed factors affecting lung cancer outcomes. Causal pathway diagrams were created as an analytical framework to propose the interrelationship between dependent and independent variables and mediating and moderating factors.

The Topic groups' main tasks were to list the potential determinants and causal factors impacting the lung cancer outcomes through a brainstorming process. The principal investigator asked the topic group members "What are the things that might affect the outcome of a patient with lung cancer?" The team was instructed to brainstorm the factors. Once the team recorded their answers, they were given a worksheet that consists of 9 categories: Physical/mental, Social, Behavior, Health Care, Environment, Family/Community, Demographic, Attitudes/beliefs, and Genetics. Upon identification and agreement on causal factors that fit under these categories as well as others by topic groups members, and the interrelationships between those factors they sketched a diagrammatic model of how these determinants are interrelated on a continuum.

The topic group members then chose the most important factors from their list to create sticky notes to begin the development of the model. Once the sticky notes were created by the factors listed from the worksheet, the modeling began by posting the final block labeled "lung cancer outcomes" to the far right and evolving the model from the left to the right to conclude all factors that impact lung cancer outcomes. The sticky notes were connected by arrows on a large wall for the participants to discuss each factor and its importance. If there was any disagreement on these causal factors or their interrelationship, consensus was reached by voting by the members that was overseen by the facilitator (Please refer to Appendix for detail on the voting system). After a collaborative review by the team, they moved factors, reviewed, edited and completed the concept model

After developing the conceptual models, the topic group members finalized the models by moving the position of the factors and adding or deleting some of the linkages using the feedback

from the group members. Picture 2 shows the first draft of the developed concept models during one of the topic group meetings.



Picture 2: e.g. First draft / developed concept model during topic group meeting

B. Review and edit topic group generated conceptual models

The community research team reviewed each TOPIC group model, reconciling overlaps and highlighting, differences. They highlighted how different experiences of stakeholder groups may add unique perspectives to the research process and may influence the conceptual model for presumed causal pathways. However, they had minimal changes to the final conceptual models. Finally, topic group members reviewed all three conceptual models (designed by each topic group), giving them the opportunity to compare their own model with the other two groups. After this step, participants were asked to draw on the models, their knowledge of the health topic, and the data acquired throughout the project, to create research questions around lung cancer outcomes. Designing the research questions based on the concept models is not the focus of this paper and it is discussed in a different publication (Rafie, et. al. submitted for publication).³⁸

Analysis of the Final Concept Models

Detailed analysis of the final topic group concept models was conducted by members of the administrative research team. Concept models were evaluated and compared for number and type of factors included in the models and the complexity of linkages between factors. Unique and common factors between concept models were identified. Factors were grouped into categories by the research team, and the presence and placement of categories was compared across models.

Table 1.1 summarizes the methods of this comparison and result of the analysis of the final 3 concept models. In this process; 3 conceptual models were first individually assessed and then in comparison, to the other 2 models. Concept models were compared for number of factors in the models, number & type of categories of factors in the model, and the number and complexity of linkages between the categories. Factors in each model were categorized using different colors, and then models were compared for similarities and differences.

| Table 1.1: Steps for analysis of the concept models | |
|--|---|
| 1 | Type of categories in each model |
| 2 | Type of causal factors in each model |
| 3 | Number of categories in each model |
| 4 | Number of total causal factors in each model |
| 5 | Number of the linkages in each model |
| 6 | Number of singular linear causal relationships |
| 7 | Number of causal factors with multiple linkages that: a) impact a factor, b) comes from the factor |
| 8 | Position of the categories & factors to the “Lung Cancer Outcome” in each model |
| 9 | Overall perspective of each model |
| 10 | Complexity of each model based on the finding from steps 1-9 |

| | |
|----|---|
| 11 | Comparison between the models based on the findings from steps 1-10 |
|----|---|

Table 1.1: Steps for analysis of the concept models

1.4 RESULTS

Three major groups participated in the SEED project, community research team, topic groups and SCAN participants. Please refer to table 1.2 for information about occupation of the participants in these groups.

| Table 1.2: Occupation of community research team, topic, and SCAN participants | | | |
|--|--|--|--|
| Stakeholder Group | Research Team | Topic Group | SCAN participants |
| Description | A multidisciplinary team of community researchers to collaboratively lead the research process | Groups of stakeholders brought together based on their experience and knowledge of the health-related topic being investigated | Consulting stakeholders who participate in focus groups and interviews – referred to here as SCAN (Stakeholder ConsultANT) participants |
| Occupation/background of the final groups | High School teacher/community organizer, practicing nurses, medical office administrator, College faculty, recent college graduate, reporter, retired nurse/patient caregiver, musician, | Lung cancer patients and caregivers, Clinical Care Providers: Practicing nurses, chaplain, social worker, home healthcare worker Access Influencers: community health workers, oncology & respiratory department directors, county board member, health insurance provider | Oncologist, pulmonologist, lung cancer survivor, health coalition director, home health provider, hospice provider, primary care physician, regional representative of the American Cancer Society and American Lung Association, Hospice consumer |

Table 1.2: Occupation of community research team, topic, and SCAN participants

Three topic groups were chosen and named “health care providers /HP”, “lung cancer survivors and caregivers /SC” and “access influencers /AI”.

The community research team consisted of eleven individuals, who were predominately female (73%) with an educational attainment above high school (91%). All were adults under age 65, with a racial mix of 55% African American, 36% Caucasian, and 9% other. Three team members left before the end of the project due to relocation and changes in work schedule. ²⁸

The three stakeholder Topic groups selected by the community research team were: 1) (non-physician) health care providers involved in some aspect of care for lung cancer patients (n = 8), 2) lung cancer survivors and caregivers of lung cancer patients (n = 7), and 3) access influencers - individuals able to influence access to detection, treatment, and survivorship care (n = 6).

Three Topic group members dropped out of the project, one from each Topic group. Like the community research team, Topic group members were predominantly female (76%), with higher than a high school education (91%). Topic group members had greater representation from adults older than 65 years (28%), with a racial mix of 38% African American, 62% Caucasian, and 5% if individuals indicating Hispanic ethnicity (Table 1.3). ²⁸

| Table 1.3: Demographics of the community research team & Topic groups | | |
|--|--|--|
| Group Name | Community Research Team | Topic Groups |
| # of participants | 11 (3#dropouts) | (8) TG-HP + (7) TG-SC + (6) TG-AI = 21 (3 dropouts) |
| Gender | Female (73%), N#8 | Female (76%), N#16 |
| Race | 55% African American, N#6 36% Caucasian, N#4 9% other, N#1 | 38% African American, N#7 62% Caucasian, N#13 5% Hispanic ethnicity, N#1 |
| Age | 18 < Adults < 65 | Adults < 65 (72%) Adults > 65 years (28%) |

| | | |
|------------------|---------------------------------|--------------------------------|
| Education | 91%, Above high school, N#10 | 91%, Above high School, N#2 |
|------------------|---------------------------------|--------------------------------|

Table 1.3: Demographics of the community research team & Topic groups

The final composition and occupation of the 3 topic groups are found in Table 1.4.

| Table 1.4: Final composition & occupation of the Topic Groups | | | |
|--|--|--|---|
| | TG-SC: Survivors & Caregivers | TG-HP: Health Care Providers | TG-AI: Access Influencers |
| Occupation of 3 Topic Groups | Male/Female, Black/White, Smoker OR Without smoking history OR exposed to smoking. (Unfortunately, occupation of TG-SC has not been recorded). | Nurse Social Worker Faith Leader Hospice Worker Physician Assistant Health Educator Department of Health | Cancer Committee Patient Navigator OSHA (Occupational Safety & Health Administration) Insurance Company Hospital administration Local Government Companies |

Table 1.4: Final composition & occupation of the Topic Groups

The Topic groups selected 10 key informants for interviews which included: 1) physicians, 2) health care service providers, 3) health organization representatives, and 4) patients. In addition, four focus groups were also conducted, with 20 individuals participating as: 1) lung cancer patients, 2) caregivers of lung cancer patients, 3) faith leaders, and 4) cancer care providers (Table 4). Final Composition of the SCAN participants are presented in Table 1.5. Information gathered from these interviews and focus groups (SCAN participants) was summarized by the community research team, and then presented and discussed with three Topic groups to inform them in the process of developing the concept models and then question development (details are presented in the methods section).

| Table 1.5: Final composition of the SCAN participants | | |
|---|-------------------------|--|
| SCAN participant | Total # of participants | Characteristics |
| Key Informant Interviews | 10 | 1) Physicians 2) Health care service providers 3) Health organization representatives 4) Patients |
| Focus Groups (#4) | 20 | 1) Lung cancer patients 2) Caregivers of lung cancer patients 3) Faith leaders 4) Cancer care providers |

Table 1.5: Final composition of the SCAN participants

Conceptual models developed by a diverse set of topic group participants captured the shared view as well as the unique perspectives of each group on the topic. Figures 1.4, 1.5 and 1.6 represents the final conceptual models developed by each topic group.

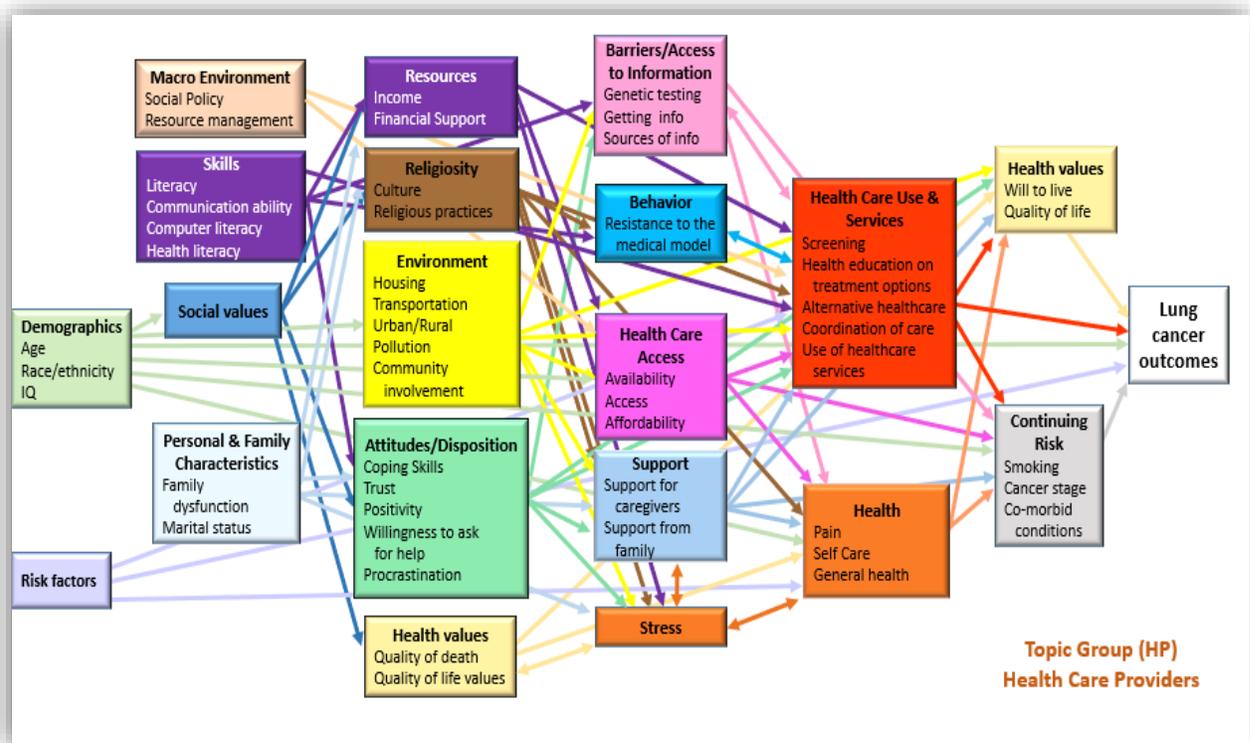


Figure 1.4: Conceptual Model developed by Health Care Providers

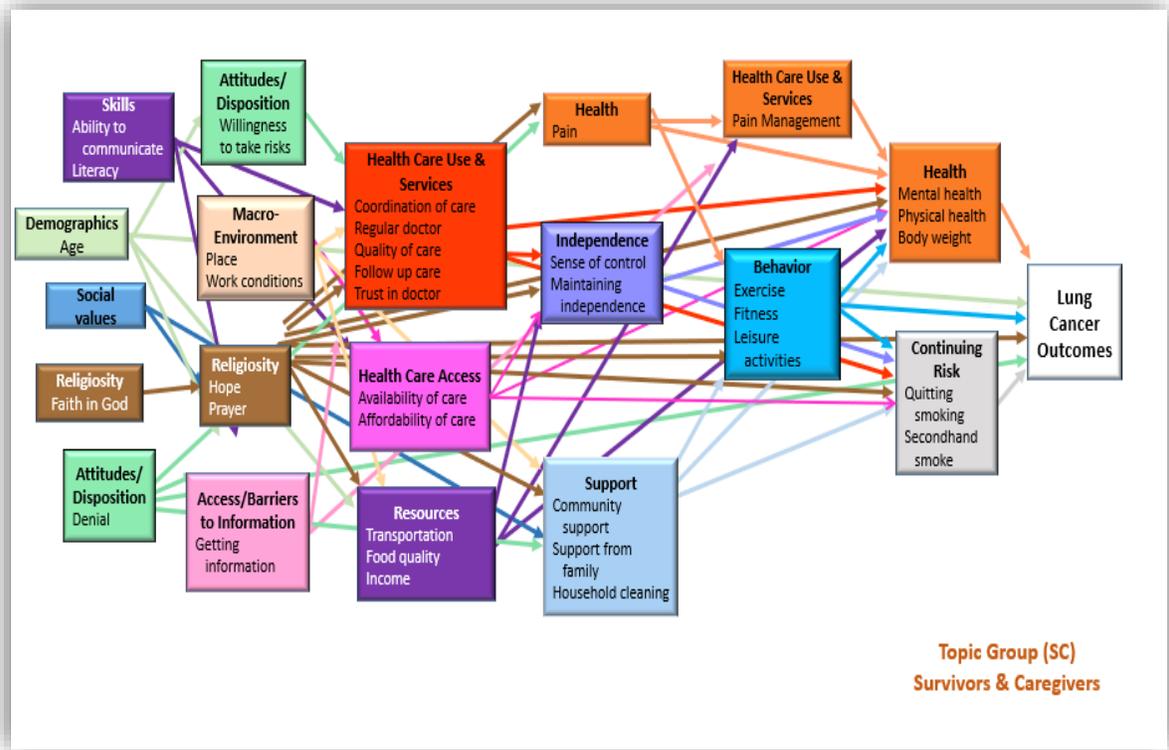


Figure 1.5: Conceptual Model developed by Survivors and Caregivers

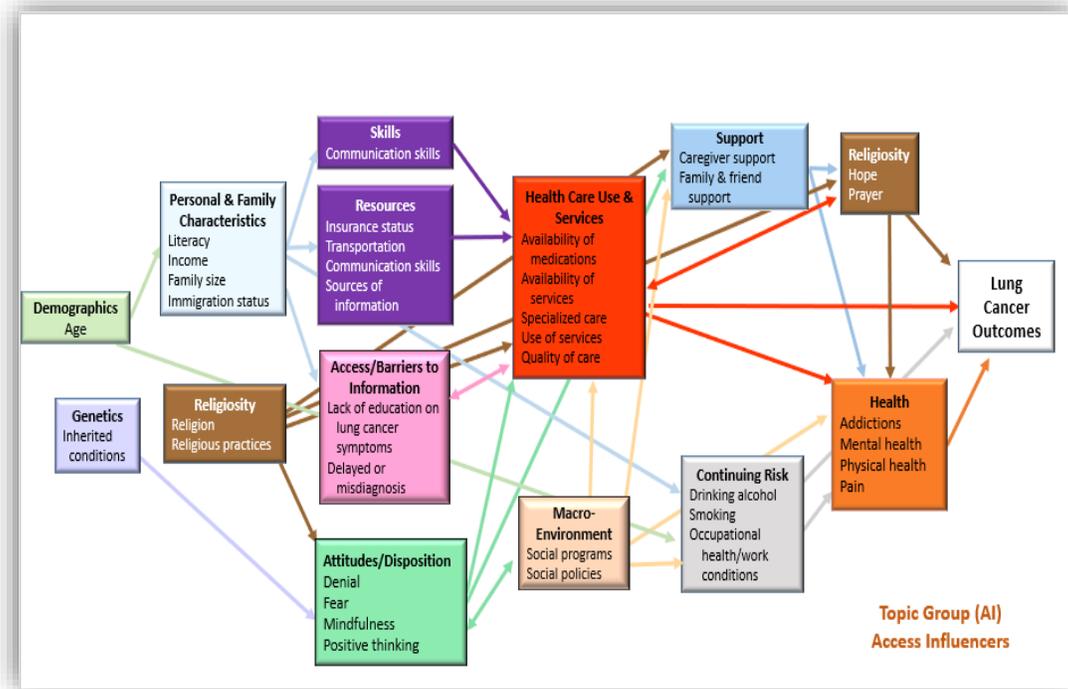


Figure 1.6: Conceptual Model developed by Access Influencers

Categories

Categories were created with the goal of maximizing the consistency (rather than diversity) across the concept models. In the process of translating the conceptual models into graphic versions, each factor contributed by the Topic groups was grouped into categories. There were 21 factor categories across the three concept models. Sixteen categories were found in two or more of the concept models, and six were unique to only one Topic group. The health care provider group had three unique categories, while the other two topic groups each had one unique factor category (Figure 1.7)

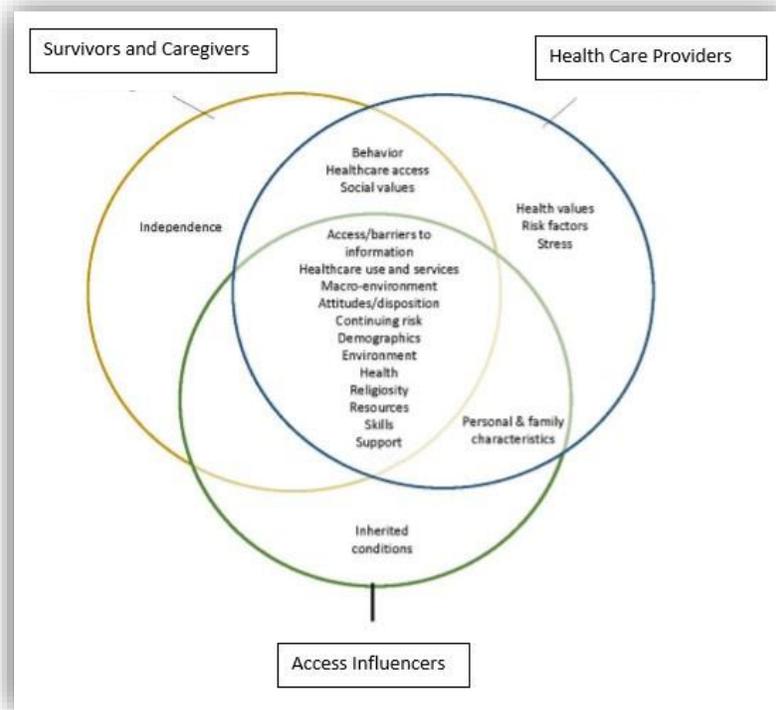


Figure 1.7: Concept Model Categories By 3 Topic Groups

Twelve categories were common among all three groups (Table 1.5), 4 categories (Behavior, Healthcare Access, Personal & Family Characteristics and Social Values) were common among 2 TGs and 5 categories were unique to only 1 TG. Among these 5 categories, 3 categories “Health values”, “Risk Factors” and “Stress” were unique to only TG-HP, and the category “Independence” was unique to TG-SC, while “Inherited Conditions” was unique to the TG-AI (Please refer to table 1.6 for more details).

| Table 1.6: Comparison of Categories Between Topic Groups | | | |
|--|------------------------|-----------------------|--------------------|
| Category | Survivors & Caregivers | Health Care Providers | Access Influencers |
| Access/barriers to information | √ | √ | √ |
| Attitudes/disposition | √ | √ | √ |
| Behavior | √ | √ | |
| Continuing risk | √ | √ | √ |
| Demographics | √ | √ | √ |
| Environment | √ | √ | √ |
| Health | √ | √ | √ |
| Health care use & services | √ | √ | √ |
| Health values | | √ | |
| Healthcare Access | √ | √ | |
| Independence | √ | | |
| Inherited conditions | | | √ |
| Macro-environment | √ | √ | √ |
| Personal & family characteristics | | √ | √ |
| Religiosity | √ | √ | √ |
| Resources | √ | √ | √ |
| Risk factors | | √ | |
| Skills | √ | √ | √ |
| Social values | √ | √ | |
| Stress | | √ | |
| Support | √ | √ | √ |

Table 1.6: Comparison of Categories Between Topic Groups

-  → Common between 3 TGs
-  → Common between 2 TGs
-  → Unique to only 1 TG

Position of the categories

The position of the categories among 3 conceptual models were compared by measuring how far or close they are located from the “Lung Cancer Outcomes” which is placed at the far-right end

of each model. The closer distance of each category to the “lung cancer outcome” means this category has more direct impact on the disease outcome. For instance, “Health Care use & Services” is a common category among the 3 concept models. The distance between this category and “lung cancer outcomes” is shortest in the model developed by TG-HP, medium in TG-AI and longest in TG-SC (Figure 1.8). This means that TG-SC believed that “Health Care use & Services” has a more indirect effect on the disease outcomes while TG-HP believed that this category has a more direct effect on the disease outcomes.

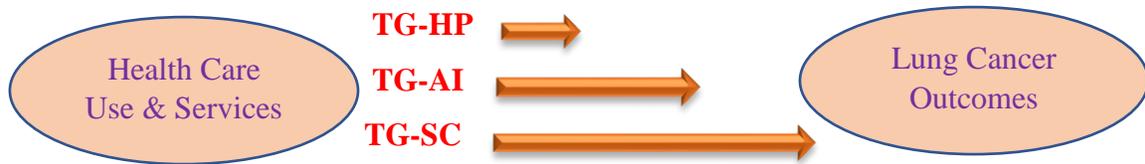


Figure 1.8: e.g. Position (distance) of the categories and disease outcomes among 3 models

The position of categories relative to lung cancer outcomes differed between models. Another example is the “Religiosity” that was positioned farthest from lung cancer outcomes by TG-SC, while directly adjacent to lung cancer outcomes by TG-AI.

The position of the categories has been used to determine the focus of each model and has been discussed in more detail from this perspective in the “Perspective of each concept model” section.

Factors

A total of 90 factors were identified between the three groups. Among these; 64 were unique to a single topic group, and 26 were found in two or more of the models. Tables 5 has listed the name of the categories and factors for the 3 concept models. Taking a closer look at the common

categories among the 3 concept models, it is observed that in addition to common factors, these categories also include different factors which represents the diverse perspective of the topic groups.

For instance, the category “Health Care Use & Services” includes the factor “Screening” in the TG-HP; “Trust in doctor” in the TG-SC and “Use of Services” in the TG-AI. This means, the same category name could have different meaning to the 3 topic group members depending on their specific knowledge and expertise. Please refer to table 1.7 for more information about factors found in each of the concept models.

| Table 1.7: Conceptual Model Factor Comparison ²⁸ | | | |
|--|--------------------------------|-----------------------------|---|
| | Unique Factors | | Factors Common to Two or More Groups |
| Lung Cancer Survivors & Caregivers | Health Care Providers | Access Influencers | |
| Body weight | Access to care | Addictions | Affordability of care |
| Community support | Alternative health care | Availability of medications | Age |
| Exercise | Cancer stage | Delayed or misdiagnosis | Availability of care |
| Faith in God | Community involvement | Drinking alcohol | Communication ability |
| Fitness | Co-morbid conditions | Family size | Coordination of care |
| Follow up care | Computer literacy | Fear | Denial |
| Food quality | Coping skills | Immigration status | Getting information |
| Having a regular doctor | Culture | Inherited conditions | Hope |
| Household cleaning | Education on treatment options | Insurance status | Income |
| Leisure activities | Family dysfunction | Lack of education on | Literacy |

| cancer symptoms | | | |
|---------------------------|-----------------------------|------------------|-------------------------------------|
| Maintaining independence | Financial support | Mindfulness | Mental health |
| Pain management | Genetic testing | Religion | Pain |
| Place | Health literacy | Social programs | Physical health |
| Quitting smoking | Housing | Specialized care | Positivity |
| Second-hand smoke | IQ | | Prayer |
| Sense of control | Marital status | | Quality of care |
| Trust in doctor | Pollution | | Religious practices |
| Willingness to take risks | Procrastination | | Smoking/quitting |
| | Quality of death | | Social policies |
| | Quality of life values | | Social values |
| | Race/ethnicity | | Sources of information |
| | Resistance to medical model | | Support for caregivers |
| | Resource management | | Support from family |
| | Risk factors | | Transportation |
| | Screening | | Use of care |
| | Self-care | | Occupational health/work conditions |
| | Stress | | |
| | Transportation | | |
| | Trust | | |
| | Urban/rural | | |
| | Will to live | | |
| | Willingness to ask for help | | |

Table 1.7: Conceptual Model Factor Comparison

Connections between Factors (Linkages)

The greatest number of connections between factors was found in the health care provider concept model with 68 connections, followed by the lung cancer survivor and caregiver model with 48 connections, and the access influencer model with 31 connections (Figure 1.9).

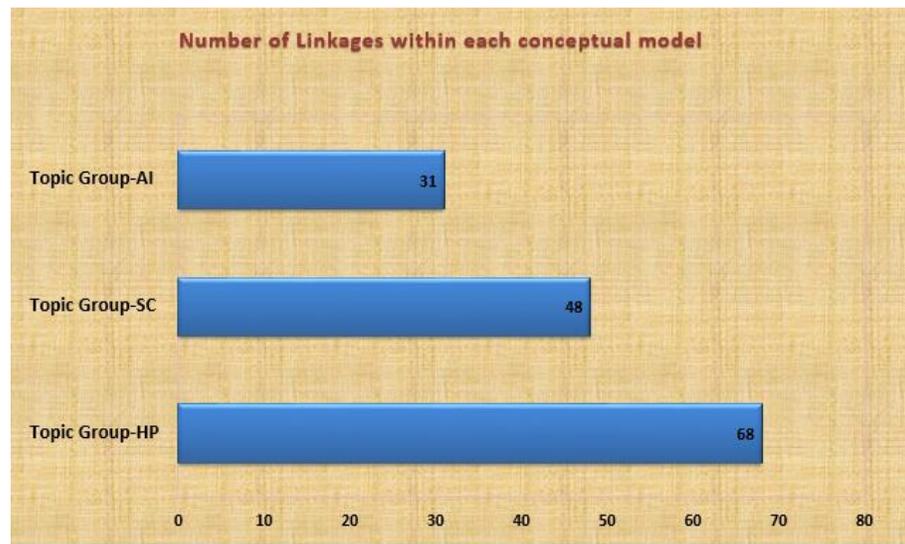


Figure 1.9: Number of Linkages within each conceptual Model

Five of the connections in the TG-HP model were bidirectional, 3 connections in the TG-AI were bidirectional and TG-SC had zero bidirectional connections (Table 1.8).

TG-HP had 5 direct connections from categories to the lung cancer outcomes, TG-SC had 6 direct connections while TG-AI had only 4 direct connections (Table 1.8). The finding that TG-SC had no bidirectional connections, but they had the highest number of direct connection to the lung cancer outcomes could possibly explain the more straightforward thinking style of TG-SC.

Table 1.8: Type of Linkages in each concept model

| Topic Group Name | Total # of connections | Bidirectional connections | Direct connection to the disease outcome |
|-------------------------------|-------------------------------|----------------------------------|---|
| TG-HP: Health Care Providers | 68 | 5 | 5 |
| TG-SC: Survivors & Caregivers | 48 | 0 | 6 |
| TG-AI: Access Influencers | 31 | 3 | 4 |

*Table 1.8: Type of Linkages in each concept model**Perspective of each concept model*

The variance in factors, categories, and their position gave a unique perspective to each model.

TG-HP emphasized health care factors and positioned them closest to lung cancer outcomes, TG-SC highlighted factors within a patient’s control such as “Behavior” and placed them closest to lung cancer outcomes, while TG-AI emphasized more on the macro-environment (Table 1.10).

To support these statements, we looked closer at the categories in the half-right side of the models to determine the type of categories that are closer to the lung cancer outcomes in each model.

The half right of the models were determined subjectively by first drawing a line between the far-right side of the “lung cancer outcome” square and far-left side of the farthest category in the left of each model. Middle of this line was marked as the half-point of each model. Content of the models to the right-side of this point were evaluated more in detail to assess the perspective of each model. Table 1.9 has listed all the categories in the half-right side of the models and table 1.10 has listed the perspective of the models based on these categories.

Table 1.9: Categories on the half-right side of each concept model

| Topic Group Name | Category Name |
|--|--|
| <u>Health Care Providers</u> (TG-HP) | <ol style="list-style-type: none"> 1. Health Care Access 2. Barriers/Access to information 3. Health 4. Health Values 5. Continuing Risk 6. Health Care Use & Services 7. Behavior 8. Support 9. Stress |
| <u>Survivors & Caregivers</u> (TG-SC) | <ol style="list-style-type: none"> 1. Behavior 2. Continuing Risk 3. Health Care Use & Services 4. Independence 5. Health 6. Support 7. Health (Pain) |
| <u>Access Influencers</u> (TG-AI) | <ol style="list-style-type: none"> 1. Macro-environment 2. Continuing Risk 3. Health Care Use & Services 4. Health 5. Support 6. Religiosity |

Table 1.9: Categories on the half-right side of each concept model

- In TG-HP there are 9 categories in the right side of the model and from those 9 categories, 4 are “Health” related (“Health Care Access”, “Health Care Use & Services”, “Health”, and “Health Values”). There were only 2 health related categories in TG-SC and TG-AI.
- In TG_SC, there are 7 categories in the right side of the model and 3 of them are categories within patient’s control (“Behavior”, “Independence” and “Continuing risk”). “Independence” is a unique category to TG-SC which is placed closer to lung cancer outcomes.

- Lastly, in TG-AI, there are 6 categories in the right side of the model and “Macro-Environment” is one of them while this category in the other two TGs is placed in the left half side of the model (further from the lung cancer outcomes).

| Table 1.10: Perspective of each concept model | | |
|--|----------------------------|-----------------------------------|
| Topic Group Name | Category Name | Factor Example |
| <u>Health Care Providers</u> (TG-HP) | Health Care Access | Screening, Health Education |
| | Health Care Use & Services | Alternative Health care |
| | Health | General Health |
| | Health Values | Use of health care |
| <u>Survivors & Caregivers</u> (TG-SC) | Behavior | Exercise, Fitness, Quitting |
| | Independence | smoking, Sense of control, |
| | Continuing Risk | Leisure activities, Body weight |
| <u>Access Influencers</u> (TG-SC) | Macro-environment | Social programs & Social Policies |

Table 1.10: Perspective of each concept model

In the next phase of the project, each topic group developed research questions from these concept models and the comprehensive literature review was conducted for these research questions. These results are reported elsewhere.⁹

Complexity of the concept models

Complexity here is defined as having a greater number of 1) Factors, 2) Categories and 3) Linkages between factors. Results of the comparison of the concept models indicated that the TG-HP produced the most complex model based on the number of factors, categories, and linkages within the model. TG-HP had more linkages, followed by TG-SC and then TG-AI. The health care provider topic group had the greatest number of factors (n=55) and categories (n=21).

The number of factors and categories for the lung cancer survivor and caregivers group (n=38 & n=19), and the access influencer group (n=37 & n=15) were similar. (Figure 1.10)

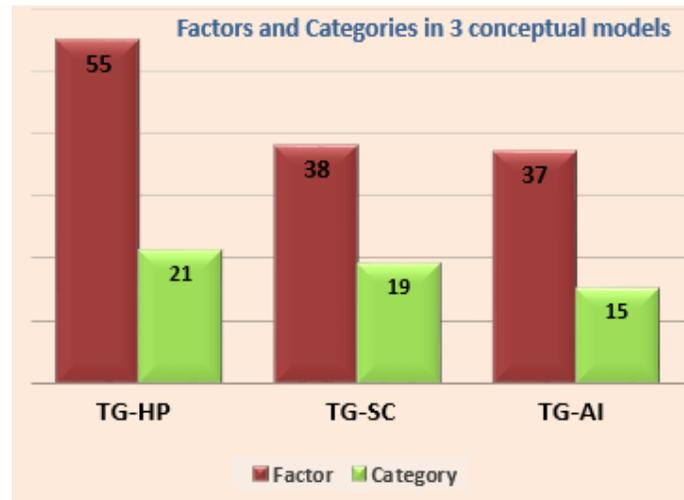


Figure 1.10: Number of Factors & Categories among 3 TGs

By combining information from figures 1.9 & 1.10 which is presented in figure 1.11 & Figure 1.12; the complexity of the concept models could be examined. Each of these figures shows data in a different way. Figure 1.11 highlights the difference between the 3 topic groups in number of linkages, factors and categories. Figure 1.12 shows interesting contrasts in the relationship of linkages to factors (and to categories) within each topic group.

It is expected to have more linkages with greater number of the categories and factors. What makes the linkages more complex is the number of links associated with individual categories, as well as the direction of those links. The main finding is the models created by topic groups with more categories, have higher number of linkages too (TG-HP).

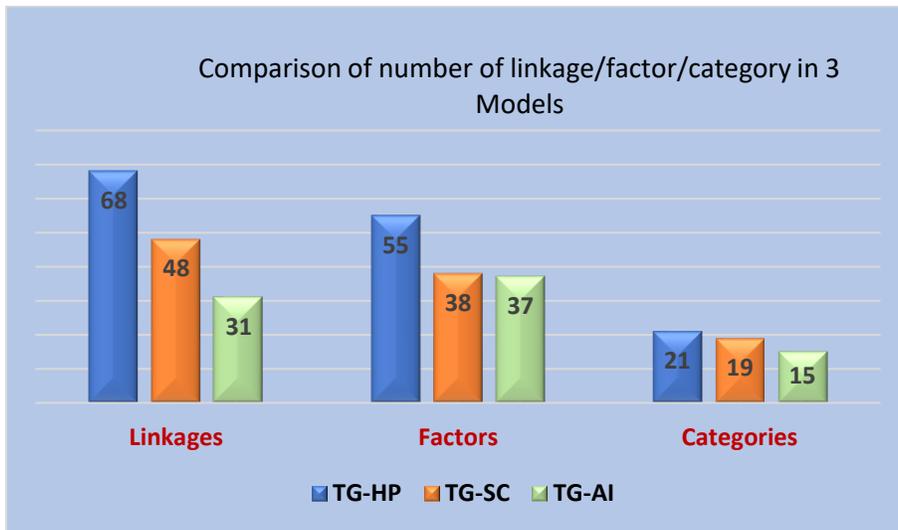


Figure 1.11: Comparison of number of linkage/factor/category in 3 Models

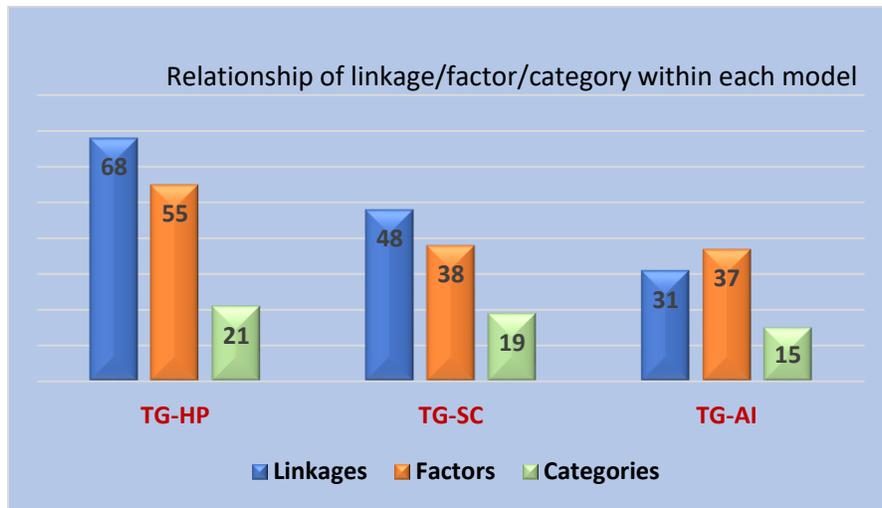


Figure 1.12: Relationship of linkage/factor/category within each model

1.5 DISCUSSION

Before creating a conceptual diagram, it is important to decide on its scope: what is the topic of interest, how many levels/types of phenomenon will be included to convey the necessary relations and what portion of the causal web or typology will be described.³⁹ The best conceptual diagrams are explicit about their scope, are informed and described by theories and/or

empirical evidence and “parsimoniously convey complex information, allowing the viewer to quickly visualize and grasp complicated relationships”.³⁹ Concept modeling is a structured method for translating complex qualitative data into a pictorial form, which displays the interrelationships among ideas in a fashion easily understood by community partners.⁴⁰

The conceptual models created during the SEED project followed this general guideline closely. The topic of interest was generated by the community, and the scope determined by the topic groups. Topic group members designed the levels and types of phenomenon (i.e. Factors) affecting lung cancer outcomes based on the processes explained in this paper which resulted from the information and evidence gathered from the community (SCAN participants). The goal was to visualize the forms of the relationship of multiple factors affecting the lung cancer outcomes in an easy to understand way.

In concept modeling, the goal is to capture not only participants’ shared views, but also the unique views of individual participants.⁵ The SEED method uses concept modeling as a critical step in evaluating a community health issue by diverse stakeholders prior to the development of research questions about the issue. After developing the concept models, topic groups developed research questions on factors affecting the lung cancer outcomes based on the concept models. More information about process of developing research questions by topic group are presented in detail in a different publication by this research group.²⁸

We used the SEED method to effectively engage key community stakeholders with diverse viewpoints in analysis of a community relevant health issue, i.e. lung cancer outcomes. The process of developing community derived concept models from diverse perspectives provided an effective framework which can be used for other health related topics. Concept models allowed

stakeholders to explore the topic in depth and produce conceptual diagrams that served as the basis for connecting the theoretic framework to empirical data, denoting the direction of causality, linking variables temporally, and mapping interactions between variables.⁶

The specific process of developing the conceptual models and the results of comparison of these conceptual models indicates that including and engaging diverse stakeholders in this project brought their important unique perspectives, as well as their shared views on the topic, that were later used to effectively develop patient centered research questions.

A lot of feedback was provided during the last 2 topic group meetings, when the relationship between the categories/factors, and how they influence each other was discussed. This was a dynamic process that lead to the final version of the concept models. There were discussions between group members with the help of the facilitator to determine and finalize the type/number of linkages, their directions and how each category/factor is related to other categories/factors in the model. For instance, “Stress” is a unique category to the TG-HP. Figure 1.13 & Figure 1.14 are the screenshots from the transcriptions of discussions during the TG-HP meeting that demonstrates how the linkages to/from the “Stress” was determined and finalized through a dynamic discussion between group members. (For details about colors and arrows refer to picture 2).

121 F2: Mk. Which is good, cause' we didn't have any arrows going to screening. **What else might it**
122 **affect?**

123 C1: **Stress**

124 F2: **Stress**, yes.

125 C2: And while we're on that, screening and health literacy affects screening.

126 C5: I think so too. Just lookin' at that.

127 F2: Health literacy. Ok. From the dark red, we're going from here, dark red to screening. Ok, that
128 was impromptu, so. (Laughing) Which is good, which is good. So jumping to cultural and
129 religious practices, right now we have been leading to resistance to the medical model/health
130 literacy and caregiver support, family support. **Anything else?**

131 C2: **Might affect stress?**

132 F2: Cultural and religious practices. Well, that's true. Ok.

133 C1: And self-care.

134 C4: What about alternative health care?

135 F2: Self-care and alternative health care. Alright, good job.

136 F1: That was cultural and religious practices?

137 F2: Yep. **Going to stress**, alternative care, and self-care. So now we have our purple box, which is
138 fortified resources, we have housing, transportation, urban, rural pollution and community

Figure 1.13: Screenshot 1 - Transcription of the topic group-health care provider meeting

149 F2: Good. **And stress?**

150 C2: Quality, quality of life?

151 F2: **She said stress**. Where's quality of life?

152 R6: Right here.

153 C4: On the same row as the purple in the bottom.

154 F2: Ah. Ok. So we're going from purple all the way over to quality of life.

155 R6: So we have, availability and access... **stress**, quality of life, and there's one other that's
156 connected—

157 C4: Caregiver and support of family.

158 F2: And also I think it was getting information.

159 C2: You could even make it go to the dark green user of health care services.

160 (Group agrees; People talking over one another indistinctly)

161 F1: Can you repeat those again?

162 C4: Coordination of care...

163 F2: So we're gonna bunch together everything that's the same color.

164 C4: Ok.

165 F2: That makes it easier. We don't have to have...purple to dark green.

166 F1: So I have four arrows coming, what do you have R6?

167 R6: Um, availability of access, which is the gray, **stress which is the green**, quality of life, which is the
168 light green, support, um, caregiver support (C4: Blue.), um, blue. And getting information on

Figure 1. 14: Screenshot 2 - Transcription of the topic group-health care provider meeting

Patients and other stakeholders bring experiential knowledge to the research endeavor that may differ in important ways from that of medical and health science researchers,^{41, 42} and their research priorities may differ based on different conceptions of what is important to learn^{43, 8, 44} or contribute to new innovations⁴⁵ and potentially improve research translation.

This means that the priority of each topic group in establishing the categories varied based on different conceptions of what was important for them to learn and focus on. A closer look at the categories identified by TG-HP, shows that their categories are more “Health” related. “Health Values” and “Risk Factors” are the categories identified by only TG-HP. Categories identified by survivors and caregivers (SC) are more “Behavior” based that are under patient’s control such as the category “Independence” which is a unique category to only TG-SC. Lastly, TG-AI’s focus is more on the Macro-environment which is a unique category to this group. Please refer to Table 7 which provides information on the emphasis of each conceptual model developed by topic groups with examples of their associated factors.

Varying emphasis of each topic group leads to a broader range of knowledge produced from the design of the concept models and enriches the final product of engaging stakeholders in research prioritization. The Community research team was effectively involved in choosing the right individuals for the topic groups in the SEED method to ensure diversity of their perspectives. However, due to the specific process of choosing the topic groups (which was based on the voting system), this method still has some limitation of ensuring the recruitment of the perfect stakeholders for this group.

We defined complexity of the models by number of 1) Factors, 2) Categories and 3) Linkages between factors. TG-HP produced the most complex model based on the number of factors,

categories, and linkages within their model. Referring to figure 10, TG-HP had greater number of factories, categories and linkages, followed by TG-SC and then TG-AI. This means the TG-HP (Health Care Provider model) produced the most complex model which could be due to their frequent exposure to the topic (lung cancer here) during their job that gives them more experience and knowledge and the fact that some of these individuals in the TG-HP could be affected by the lung cancer personally (such as being a caregiver, smoker, etc.).

It is necessary to note that the term “complexity” here is a subjective definition and could include different elements elsewhere. Because no similar study was found in the literature on examining and comparing different concept models; the study team defined the term subjectively for comparing the 3 concept models. Therefore, the method to determine the complexity of the models, is not a previously tested method in the scientific literature and could contain limitations. Even though the TG-HP produced the most complex model, the lessons learned from developing the concept models and their unique characterizations along with the common criteria among the models reveals the importance of engaging diverse group of stakeholders that could bring their unique perspective as well as their shared view of the topic.

1.6 LIMITATIONS

In a study by Hoffman et.al the principles that contribute to the successful engagement of stakeholders in the research process are identified as: 1) ensure a balanced representation of all stakeholder groups; 2) get stakeholders to "buy in" to the process and make sure that they clearly understand their roles; 3) provide neutral, expert facilitation of the stakeholder discussions; 4) establish connections among the stakeholders; and 5) keep the stakeholders engaged throughout the research process.⁴⁶

We believe that the technical trainings provided to the stakeholders prior to the concept modeling that is part of the SEED Method successfully helped to maintain these principals, as did the availability of the facilitation tools to lead the teams through the process of stakeholder selection, concept modeling, and research question development and prioritization. However, the potential limitations of implementation of this method of concept modeling for other health topics or in different communities could be availability of the diverse set of stakeholders in the area and the lack of resources to recruit a balanced representation of stakeholders and provide required technical training to them prior to the successful creation of the concept models.

Sometimes recruitment was complicated by short timelines (such as when there were delays with IRB approvals of recruitment materials) or non-response. We continued to look for recruitment venues until we reached recruitment targets such as using the newspaper ads to recruit patients and caregivers, which proved to be a successful tool.

Challenges related to stakeholder engagement were minor. They included tailoring activities to the needs and skills of different participants, such as those with low literacy. Another issue had to do with the logistics of keeping up attendance throughout the project and people arriving late.

It is possible that the length of the process to create the concept models could be shortened. In its current form, each of the 3 topic groups had 2 separate meetings (each meeting: 2/5 hours long) to design and finalize the concept models. A shortened timeline with a more simplified process that could be achieved with allocation of less resources to provide the required training of the stakeholders could broaden the application of this method to similar settings.

1.7 CONCLUSIONS

The development of community-informed interventions can only be done by involving community members early in the research process.⁵ Concept modeling is an affordable method to engage the community, identify individuals interested in joining the research team, and assess community needs in a community-friendly format. Like CBPR, concept modeling fosters rapport between researchers and community members through a system of data collection and analysis that incorporates community input into all stages of research.⁵

The SEED Method effectively engages key community stakeholders with diverse viewpoints in analysis of a community relevant health issue. Community derived concept models provided an effective framework around which collective responses and patient-centered research questions can be developed. This has transformative potential in terms of integrating stakeholders into the research process, improving stakeholder relations, and generating new research topics and approaches.

The process for selecting diverse groups of patients, health providers, and other relevant stakeholders that is part of SEED, leads to a broader range of knowledge produced in the design of the concept models, enriches the final product of prioritized research questions, and could potentially improve the process of the research translation to address the health issue of focus.

1.8 FUTURE RESEARCH & DIRECTION FOR THE CONCEPT MODELING

While this research suggests potential impact of stakeholder engagement, systematic characterization and evaluation of engagement at multiple stages of research is needed to build the evidence base.⁴⁷

In the next stages the research team will gather evidence about the impact of the research agendas generated by these demonstrations, tracking the responses of target audiences, how they envision using the information, and whether any of these questions impact funding or research decisions. An overarching goal of the SEED method is that the needs and priorities of stakeholders that have driven these questions will provide impetus and support to addressing these questions. A longer-term goal is to encourage others to develop stakeholder research agendas using this methodology and to develop a repository of such efforts.

1.9 ACKNOWLEDGEMENT

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CHAPTER 2

Title: Exploration of Lung Cancer Screening Barriers in a Medically Underserved Area

2.1 ABSTRACT

Background:

Each year, more people die of lung cancer than of colon, breast, and prostate cancers combined. The knowledge that lung cancer can be successfully treated if caught early; has driven a decades-long search to find an accurate and reliable screening test. The National Cancer Institute's National Lung Screening Trial (NLST) found that asymptomatic patients aged 55 to 74, with a smoking history of at least 30 pack-years, and a current or former smoking history (quit less than 15 years ago), had a 20% reduction in risk of death from lung cancer, if they were screened with annual Low-Dose CT (LDCT). Findings of this trial resulted in that LDCT became the gold standard of screening for lung cancer. This study is designed to evaluate 1) referring health care providers' knowledge and attitudes toward LDCT, and their perspectives on patient barriers to compliance with lung cancer screening, 2) knowledge, attitudes and beliefs of patients toward lung cancer screening, and screening barriers among early compliers and late compliers, 3) analyze the similarities and differences of screening barriers between these two patient groups, and 4) compare the lung cancer screening barriers from the perspective of health care providers and patients.

Methods:

We conducted 2 surveys among 1) health care providers who refer patients for LDCT to screen for lung cancer in Martinsville, Henry County, Virginia, and 2) patients who received LDCT in the past 3 years in the Memorial Hospital of Martinsville, Virginia. We surveyed 24 health care providers (48.9% response rate) and 49 patients (35.2% response rate) from November 2017 to February 2018. These two surveys included questions on knowledge and attitudes toward lung cancer screening specific for each group and a common question on barriers to lung cancer screening with the goal of comparing the responses from the perspective of the health care providers and patients.

Results:

Providers are mostly white (91.6%), equal female/male distribution, and age range 55 to 59 (45.8%) with 41.6% of them practicing as a family physician. Patients are mostly white (85.7%), more female (61.2%), heavy smokers (average 41.1 years smoked in the past), low income (28.5% under \$15,999 annual income), and age range 55-75 (83.6%). About 66.6% of the providers think that LDCT can save lives and 87.5% of them think that there should be a screening guideline for high risk populations. Among the early complier patients “*having insurance that covers the cost of the screening*” is the main screening facilitator and “*Being unaware of lung cancer screening services*” is the major barrier for most of the late compliers. Comparison of the responses of the providers and patients to the common question on the lung cancer screening barriers, reveals that the most important barrier for both groups, is the “*lack of family and social support to help them get the screening*”. The least important barrier for health care providers is “*transportation*” and the least important barrier for patients is that “*People cannot afford the cost of lung cancer screening*”. While “*There is not enough time to discuss*

lung cancer screening with physicians” is the second most important barrier (order # 2) for health care providers, it is less important for the patients (order # 6).

Conclusion:

Health care providers and patients have similar as well as distinct barriers to lung cancer screening. They both view “*lack of social and family support*” as the most important barrier to lung cancer screening but there are some differences on how they view other barriers. Identifying these differences enables health care providers, policy makers and public health professionals to focus on addressing the most important barriers first. This statement is also true about findings of this study about screening facilitators among early compliers and the screening barriers in late complier patients. This is more important in communities with limited resources that need to prioritize actions to improve lung cancer screening referral and compliance.

Key Words: Low-Dose Computed Tomography (LDCT), Health care provider, lung cancer, screening barriers, attitude, knowledge.

2.2 INTRODUCTION

Lung Cancer & Importance of Early Diagnosis

Lung cancer is the second most common cancer in both men and women (not including the skin cancer) and is by far the leading cause of cancer death among both men and women. Each year, more people die of lung cancer than of colon, breast, and prostate cancers combined.⁴⁸ Lung cancer deaths for men and women are declining; however, more people still die of lung cancer each year than of breast, colon, prostate and pancreas cancer combined.⁴⁹ The number of new cases of lung and bronchus cancer was 55.8 per 100,000 men and women per year. The number of deaths was 44.7 per 100,000 men and women per year.³ These rates are age-adjusted and based on 2010-2014 cases and deaths.⁵⁰

David E. Midthun (2013) states in his paper that “A humbling feature of lung cancer is that most patients have evidence of spread at the time of presentation. Approximately three quarters of patients with lung cancer will present with symptoms, and the majority of these have an advanced stage of tumor at the time of diagnosis”.⁴⁹

When lung cancer is confined to the lung at the time of diagnosis, five-year survival is 53.5%.⁵¹ This drops to 26.1% when there is regional nodal involvement and to 3.9% when there is distant metastatic disease.⁵¹ In the period from 2003 through 2009, only 15% of lung cancer cases were diagnosed at a localized stage.⁵² The goal of screening is to shift the timing of the diagnosis to an earlier point, so that the disease is localized to the lung, and appropriate therapy can reduce lung cancer mortality.⁵²

Given this scenario, early detection of lung cancer through screening is fundamental in improving disease outcomes, reducing deaths and increasing survival rates. The knowledge that

lung cancer can be successfully treated if caught early; has driven a decades-long search to find an accurate and reliable screening test. Despite the recent public policies establishing coverage for lung cancer screening among high-risk populations,⁵³ lung cancer screening awareness, access, and utilization remain low, particularly among underserved populations.⁵⁴

Therefore, the Society for Behavioral Medicine (SBM) encourages health care providers and health care systems to examine the structural barriers that may impact lung cancer screening uptake and investigate ways to expand screening access to underserved high-risk populations.⁵⁵

Results from many lung cancer screening trials around the world, including Japan, the United States, Italy, Denmark, and the Netherlands, have shown that screening for lung cancer with low-dose CT (LDC) can result in an increase in the detection of lung cancer at an earlier stage, when it can be more effectively treated.^{56,57,58}

The recent recognition of Low-Dose CT as an effective lung cancer screening tool among high risk patients, and coverage of the procedure by Medicare and other health insurers have created the need for physician instruction in risk assessment guidelines and identification of the barriers to patient compliance with lung cancer screening recommendations.

Many practices and institutions have experienced barriers in their attempts to implement successful screening programs, these include challenges in maintaining the same high caliber of the screening program in the NLST; confusion regarding insurance reimbursement protocols, and a lack of resources to help physicians discuss the specifics of LDCT screening with their patients.⁵⁹

The purpose of this study is to evaluate the knowledge and attitudes toward lung cancer screening and barriers to this screening among health care providers and patients in a rural, medically underserved area in Virginia to discover the primary factors contributing to lung cancer screening uptake from the perspective of the health care providers and patients.

Our main research questions are:

1. What are the differences and similarities between barriers to lung cancer screening from the perspective of the health care providers and patients?

We hypothesized that health care providers and patients have similar as well as distinct barriers to lung cancer screening.

2. What are the facilitators to lung cancer screening among patients who received the screening on time after a physician's recommendation (early compliers) and what are the barriers for those who received the screening late after a physician's recommendation (late compliers)?"

We hypothesized that patients who received the screening on a timely manner have specific facilitators in helping them to get the screening and patients who got the screening late, have specific barriers that prevented them from getting the screening on time.

We aim to evaluate 1) referring health care providers' knowledge and attitudes toward LDCT, and their perspectives on patients' barriers to compliance with lung cancer screening, 2) knowledge, attitudes and beliefs of patients toward lung cancer screening, and identify screening facilitators among early compliers and screening barriers among late compliers, 3) analyze the screening barriers and screening facilitators between early compliers and late compliers, and 4)

compare the lung cancer screening barriers from the perspective of health care providers and patients.

By comparing the screening barriers and patient characteristics of those who received lung cancer screening in a timely fashion, with those who delayed in receiving screening after a physician referral; this study will gather valuable information about the characteristics of patients most at risk for screening non-compliance and identify the key barriers for those patients.

Future interventions could be developed to target the identified barriers through dissemination of the findings of this study to the referring physicians. The results of this study have the potential to inform screening initiatives and referral procedures in communities with similar characteristics to Martinsville.

Conceptual Framework

The Health Behavior Framework (HBF) ⁶⁰ served as a conceptual framework to guide this study. This framework represents a synthesis of some of the major theoretical formulations in adherence and health behavior. ⁶¹ It considers the context within which a desired behavior occurs including provider characteristics and health care settings, as well as community and social influences. ^{62,63,64} The HBF domains include individual factors (knowledge, past health behaviors / here smoking history, facilitators and barriers to screening, social norms and support, and communication with providers/here: physician recommendation), health care factors, and health insurance coverage. These factors have been considered in this study.

This conceptual framework specifies that behavioral influences can be culturally determined and allows for the identification of new constructs ⁶¹ (why patients don't get screening after doctors' recommendation or have delay) and factors that are relevant to a health behavior or population.

The HBF has been successfully used in previous research, addressing other cancers such as cervical cancer and liver cancer. ^{65,66,67}

SEED project and design of this study

The SEED Method involves community members at three levels of engagement: collaboration, participation, and consultation, thereby accessing the opinions and experience of a broad base of stakeholders. Diverse community stakeholders from different socioeconomic, educational, and professional backgrounds were effectively engaged using the SEED method in modeling the factors that impact lung cancer outcomes in their rural community of Martinsville, VA, and in developing an actionable research agenda from November 2015 to July 2016. The final research agenda consisted of 12 research questions (appendix) that community stakeholders designed (using the SEED method) and believed to be the concern of that community which needs to be the focus of future research. More information about the research agenda can be found in a publication by Rafie, et al. ⁶⁸ Detailed information about the SEED method is available in the SEED toolkit ⁶⁹ and the SEED brochure in the appendix.

A comprehensive literature review was conducted by the study team on the final research agenda which was produced from the SEED project. The goal of this literature review was to avoid duplication of research to help focus the future research on gaps identified in the literature. From 12 final research questions, 2 questions were chosen to be the focus of this study. This means the present study is based on the gap identified as a result of a literature review for these two questions.

These 2 questions are:

1. If society requires insurance companies to offer free annual cancer screenings, would lung cancer be diagnosed earlier?
2. If the primary care physician recommended regular screenings would patients receive them?

The literature review for these two questions revealed a gap of information on screening barriers among specific population groups, particularly patients with low socioeconomic status and high-risk smokers. Therefore, patients who have been referred to get the screening for lung cancer were chosen to be the target population because they live in an underserved area (Martinsville) and are high risk smokers (the eligibility requirement to get the screening by Medicare).

On the other hand, health care providers who refer patients to get this screening in the area also were chosen to be the second target population. The goal is to identify specific barriers to lung cancer screening that exist in this area from the perspective of the health care providers and patients. This study will help to explore the dynamics with referring physicians to inform policy makers in establishing interventions and strategies that address these barriers and promote lung cancer screening compliance.

Low-Dose Computed Tomography (LDCT)

The International Early Lung Cancer Action Project (I-ELCAP) study team found that Low-Dose CT (LDCT) was able to detect malignant disease 4 times more frequently than were chest radiographs.⁷⁰ A year later, the National Cancer Institute's National Lung Screening Trial (NLST)⁵⁹ found that asymptomatic patients aged 55 to 74, with a smoking history of at least 30 pack-years, and a current or former smoking history (quit less than 15 years ago), had a 20%

reduction in risk of death from lung cancer, if they were screened with annual LDCT rather than with X-ray, for 3 consecutive years. The results of this trial were released to the public in 2011 and led to organizations such as the US Preventive Services Task Force (USPSTF)⁷¹ and the American Cancer Society⁷² to reconsider and change their lung cancer screening guidelines and recommendations. The US Preventive Services Task Force recommended annual lung cancer screening with Low-Dose CT for high-risk patients in December 2013.⁷³

The findings of the landmark National Lung Screening Trial (NLST)-showing a 20% reduction in lung cancer mortality when screening with LDCT, compared with chest radiography marked a turning point in the field of lung cancer screening, influencing organizational recommendations and leading to increased acceptance of LDCT for screening of individuals at high risk for lung cancer.⁵⁴

One large randomized trial reported that screening persons aged 55 to 74 years who have cigarette smoking histories of 30 or more pack-years and who, if they are former smokers, have quit within the last 15 years reduces lung cancer mortality by 20% and all-cause mortality by 6.7%.⁷⁴ An updated analysis showed that the estimated reduction in lung cancer mortality was 16%.⁷⁵

In January 2013, the American Cancer Society issued the following guidelines for lung cancer screening; “Clinicians with access to high-volume, high-quality lung cancer screening and treatment centers should initiate a discussion about screening with apparently healthy patients aged 55 years to 74 years who have at least a 30–pack-year smoking history and who currently smoke or have quit within the past 15 years.”⁵² Currently, the “gold standard” test to screen and diagnose for lung cancer is Low-Dose Computed Tomography (LDCT).^{76,77,78} A process of

informed and shared decision-making with a clinician related to the potential benefits, limitations, and harms associated with screening for lung cancer with LDCT should occur before any decision is made to initiate lung cancer screening”.⁷⁹

Barriers to Lung Cancer Screening

There have been numerous research studies conducted on barriers to uptake of lung cancer screening among high risk populations. These studies have assessed either high risk populations or health care providers as their target population. However, there is lack of literature on the studies to examine both groups at the same time. This study is the first that has been designed to evaluate and compare the barriers to lung cancer screening from the perspective of the patients as well as health care providers.

Barriers to lung cancer screening among high risk populations

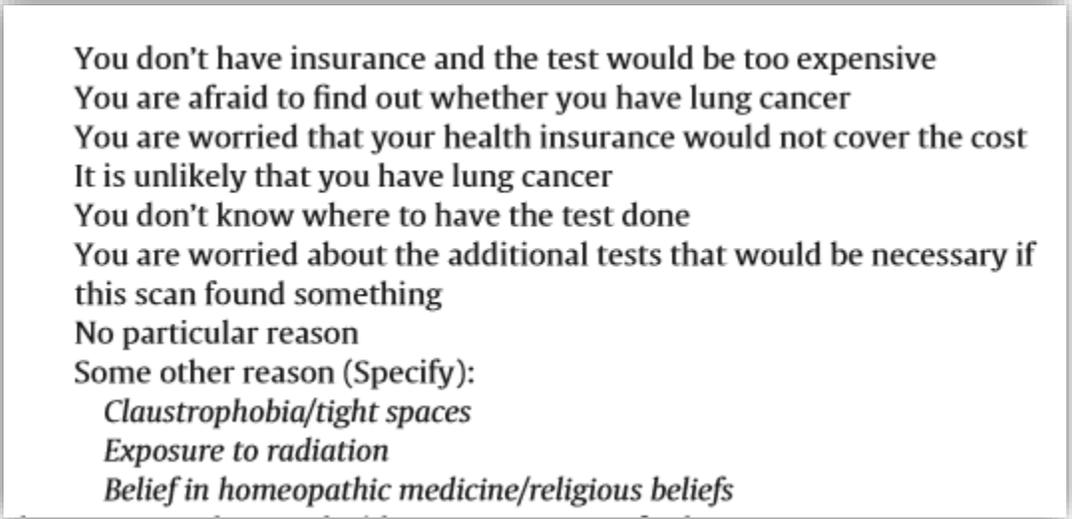
Sin et al. (2016) has examined sociocultural barriers to lung cancer screening among Korean immigrant men. Even though this study was conducted on a specific population, it is one of the unique studies in the scientific literature that has explored barriers to this screening as well as facilitators. The barriers that are identified by Sin et al. are presented in figure 2.1:

| Facilitators | Barriers |
|---|---|
| Positive aspects of the health care system in South Korea | Costs of health care in the US |
| Recommendations from others | Lack of time (because of competing demands) |
| Physicians | Lack of knowledge (about lung cancer and screening) |
| Family members | Attitudes about prevention |
| KWA | Lack of physician recommendation |
| Interest in health (in health screenings and programs) | |
| Existing health problems and respiratory symptoms | |
| Health consequences of aging | |

Figure 2.1: Facilitators & barriers to screening/is taken from the study published by Sin et al.

Delmerico et al. (2014) has studied patients' willingness and barriers to receiving a lung cancer screening.⁸⁰ The following questions were asked from participants to identify the barriers and facilitators of getting the screening. The authors have listed the reasons for each question.

1. Which of the following reasons would you say is important to you for NOT getting this test?
(to identify the barriers, Figure 2.2)
2. Which of the following reasons would you say is important to you for getting this test?
(to identify the facilitators, Figure 2.3)



You don't have insurance and the test would be too expensive
You are afraid to find out whether you have lung cancer
You are worried that your health insurance would not cover the cost
It is unlikely that you have lung cancer
You don't know where to have the test done
You are worried about the additional tests that would be necessary if this scan found something
No particular reason
Some other reason (Specify):
Claustrophobia/tight spaces
Exposure to radiation
Belief in homeopathic medicine/religious beliefs

Figure 2.2: Screening barriers (Delmerico et al.) 40

You want to be able to diagnose lung cancer as early as possible
You want to follow your doctor's recommendations
You feel you are at risk for lung cancer
You are sick or have had medical problems
Some other reason (Specify):
Early Detection
Experienced lung cancer in family or friend
For children/family
Health problems/symptoms
Past exposure

Figure 2.3: Screening facilitators (Delmerico et al.) 40

Other researchers such as Cataldo et al. and Jonnalagadda et al. have explored the perceptions, attitudes, and beliefs about lung cancer screening among high risk individuals.^{81,82} The study by Cataldo et. al. concluded that cognitive aspects of participation in screening are key to increasing the uptake of lung cancer screening among high- risk smokers. Some authors have classified different barriers to lung cancer screening into broad categories. For instance, Ali et al. have explored barriers to uptake and have divided them into practical barriers (such as transportation) and emotional barriers (such as fear).⁸³ Other researchers like Quaife et. al. has focused on attitudes toward the screening as a barrier to the screening within socioeconomically deprived and heavy smoking communities and have explored attitudes of this specific population further.⁸⁴ Quaife et. al. (2014) has stated the following attitudes as a barrier to lung cancer screening: 1) fear that screening was too late, 2) control over lung cancer (other causes, fatalism, lung cancer as incurable), and 3) concern about treatment (living without lungs, quality of life).

Barriers to lung cancer screening among health care providers

Ersek et. al. states that there are gaps in physician knowledge about screening guidelines and reimbursement, and this indicates a need for further educational outreach.⁸⁵ Lewis et. al. has studied Low-Dose CT for lung cancer screening practices and attitudes among primary care providers and has identified the perceived barriers to lung cancer screening as: 1) patient cost (86.9%), potential harm from false-positive findings (82.7%), patients' lack of awareness (81.3%), risk of incidental findings that will require further workup or monitoring (81.3%), and lack of insurance coverage (80.1%).⁸⁶

Some researchers have identified the relationship between the doctors and patients as a potential barrier in uptake of the lung cancer screening especially among patients with low health literacy level. Price-Haywood et. al. (2014) has looked at two different methods of communication (comparative effectiveness of audit-feedback Versus Additional Physician Communication Training) to improve compliance with cancer screening for patients with limited health literacy.

⁸⁷ This study shows that physicians can be trained to achieve and maintain patient-centered communication skills.⁸⁷

Moreover, lack of the knowledge of health care providers of who is less likely to participate in the screening could be a barrier. This has been discussed in the publication by Ali et al. that high-risk individuals who are older, female, smokers, from a lower socioeconomic group, or with a higher affective risk perception are less willing to participate in the screening trials.⁸³ In a recent publication by Lm. et. al., researchers at University of North Carolina, Chapel Hill, surveyed 100 resident primary care physicians and 86 attending primary care physicians on lung cancer screening-related opinions and practices. Most attending and residents agreed that barriers to screening included limited time during patient visits (62% and 78%, respectively), cost to

patients (74% and 83%, respectively), potential for complications (53% and 70%, respectively), and a high false-positive rate (67% and 73%, respectively).⁷³

Compliance with physicians' recommendation for screening

“Lack of physician recommendation” for lung cancer screening has been identified as a barrier to screening in the scholarly articles. Sin et al. have conducted a qualitative study in the form of focus groups and interviews to find the barriers that prevent Korean men who immigrated to the US, from getting the lung cancer screening. This study was published in 2016, a few years after LDCT has been identified as a gold standard test to screen for lung cancer. However, “most participants stated their health care providers had never recommended Low-Dose CT to them”.⁶¹

One of participants in this study stated:

“I have never heard of it (Low-Dose CT). My family physician did not tell me about this. Unless a doctor recommends you get one, it is not possible to just ask and receive a CT scan”.⁶¹

Other articles have indicated that some patients decide not to get screened, even after receiving a physician recommendation which is due to other contributing factors. Delmerico et al. has designed a study to evaluate the barriers to lung cancer screening among a group of current and former smokers. In this study, participants who had not had a CT scan for lung cancer in the past 12 months were asked about their reasons for not doing so. Those who had this test were asked about their reasons for having it. One of the questions asked to participants was “Would you have this test if it were recommended by your doctor?” In response to this question, 78.5% of current smokers and 81.4% of former smokers indicated that they would. Those who said they would refuse a CT scan were asked why not. Among current smokers, the most commonly cited reasons were: not wanting to find out if they had cancer, and lack of insurance. Among former

smokers, the most commonly cited for not having the screening was a belief that they did not have lung cancer.⁸⁰

2.3 METHODS

The main goal of this study was to assess the knowledge, attitudes, and barriers to lung cancer screening among health care providers and patients in Martinsville/Virginia. The results of this study would help to better understand the current lung cancer screening practices and challenges in receiving the lung cancer screening. In the United States, many adults who are at a high risk of developing lung cancer don't get the screening even after a recommendation from their physicians. This project is exploring the difficulties and reasons for why these individuals don't get the screening; from the perspective of the health care providers and patients.

In other words, what the patients say about factors preventing them from getting the screening and what the physicians think about it. Health care providers that screen and refer patients for LDCT to screen for lung cancer, and patients who received this test in the past 3 years, are the study's target populations. Approval from the IRB was obtained before any initiation to collect information from these 2 groups of participants. The IRB approval letter is available in the appendix.

Process of Identification & Recruitment of the Participants

This study was conducted in collaboration with the Memorial Hospital of Martinsville / Henry County, because this location is a rural, relatively underserved area with a hospital that has recently begun promoting lung cancer screening by LDCT. This hospital facilitated and assisted the identification and recruitment of the potential participants (health care providers and patients).

The study team collaborated with the director of physician relations and business development at Martinsville hospital to invite the health care providers to participate in the study. This person introduced the providers to the study during his routine weekly visits to their practice sites and provided their e-mails to the study team. Invitation e-mails were also sent out to the providers as a reminder about the study. The following diagram (Figure 2.4) presents how the hospital facilitated the process of identification and recruitment of the patients along with the different steps of the study.

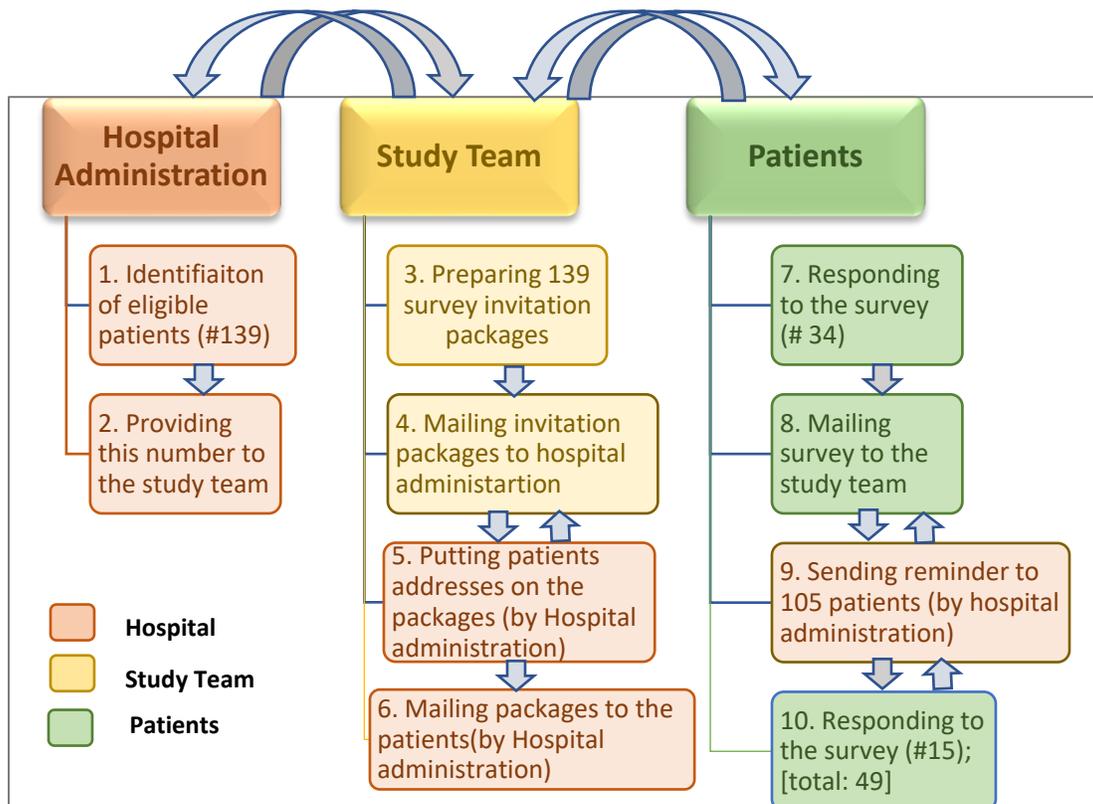


Figure 2.4: Process of patient recruitment

The hospital administration conducted the search of patients receiving an LDCT for lung cancer during that time. There were 139 patients who had this screening since the beginning of 2015. The hospital mailed the pre-prepared invitation packets to these patients on behalf of the study team, on January 4th, 2018. The invitation packages included 1) a letter from the Martinsville administration (with a link to the online survey), 2) the paper survey, 3) a contact information release form (to receive a gift card) and 4) a prepaid return envelope. The hospital letter and contact information release form are included in the appendix.

The process of patient recruitment (Figure 2.4) was conducted from October 2017 to February 2018. This timeline is shown in Figure 2.5.



Figure 2.5: Study timeline

*” Steps” in Figure 2.5 refer to the numbers in Figure 2.4.

Data Collection: Health care providers

A 28-item survey was designed to collect the information from health care providers based on previously tested lung cancer screening questionnaires with a similar population.^{85,86} Permission

was obtained from the authors (permission e-mails are in the appendix). The following question categories included in the health care providers survey: (1) Lung Cancer Screening Barriers (2) Practice Characteristics (3) General Information about Lung Cancer Screening (4) Demographic Information. The hospital provided a list of 49 health care providers who would be likely to screen patients for lung cancer risk and refer them for lung cancer screening. From 49 providers who were approached, 24 providers finally participated in the study.

Data Collection: Patients

A 22-item survey was designed to collect the information retrospectively from patients who had received lung cancer screening (Low-Dose CT / LDCT) at the Martinsville Henry County Memorial Hospital within the past 3 years. Questions from validated questionnaires in the literature on lung cancer screening (that were administered to patients) were used to design this survey.^{61,80} Questions on smoking history were designed using the National Adult Tobacco Survey (NATS) from the Center for Disease Control and Prevention (CDC).⁸⁸ The patient's survey aimed to address beliefs, knowledge, and attitude of the patients relative to lung cancer risk and screening, and barriers to lung cancer screening. The following categories were included in the final survey for patients: (1) Lung cancer screening barriers (2) General Information about Lung Cancer Screening (3) Smoking Information (4) Personal Lung CT Screening History (5) Demographics Information.

The questions about barriers asked participants to rate each of the known patient lung cancer screening barriers (derived from the literature) for level of significance in their decision making on a scale of 1 to 10. The barrier question was repeated in the health care providers' survey, so their responses could be compared. Moreover, the patients' survey included a question "Did you receive lung cancer screening within eight weeks of the recommendation from your physician?"

Yes / No. “Patients responding “No” (Late compliers) were directed to a line of questioning that identified the primary screening barriers that caused these patients to wait to be screened. Here they can choose from the list of the common screening barriers which are found in the literature. There is also an open-ended question that ask them to write if they had a different barrier not listed among the common barriers.

Patients who answered “Yes” (Early compliers) were directed to another question that had a list of the facilitators that helped them to get the screening on a timely manner. These facilitators are the most common screening facilitators found in the literature.^{61,80} There is “other” option to allow patients (early compliers) to write if they had a different facilitator not listed in the question.

Some of the participants were participated in the online version of the survey (designed by Qualtrics). Responses from participants to the paper survey, were entered manually into Qualtrics by the study team. The report of all the survey responses was downloaded from Qualtrics and at the same time, data was extracted as an excel file. This data was analyzed using statistical “R” software.

2.4 RESULTS

The responses from the patients and health care providers first were assessed individually and then their responses to the common question of screening barriers were compared to each other. The common question on screening barriers is designed based on the scholarly articles in the literature which is described previously. For a list of the most important screening barriers found in the literature, please refer to table 2.1.

| Table 2.1: Ten most common screening barriers | |
|---|---|
| Barrier ID | Screening Barrier |
| B1 | People's fear of finding lung cancer |
| B2 | People don't think lung cancer screening would help |
| B3 | Peoples' concern for radiation exposure |
| B4 | People are unaware of lung cancer screening services |
| B5 | People cannot afford the cost of lung cancer screening |
| B6 | People don't think insurance will cover lung cancer screening |
| B7 | There is not enough time to discuss lung cancer screening with physicians |
| B8 | People don't have family and social support to help them get the screening |
| B9 | People think timely screening, will not have effect on diagnosis or disease outcome |
| B10 | Transportation difficulties |

Table 2.11: Ten most common screening barriers

Results: Health care providers

Surveys were distributed between November 2017 and December 2017 among 49 health care providers who were identified by the Hospital as likely to screen for and recommend LDCT for lung cancer. From these 49 providers, 24 completed the survey with a response rate of 48.9%.

Health care providers' characteristics

Characteristics of these health care provides are presented in table 2.2. Providers are mostly white (91.6%), equal female/male distribution, and age 55-59 (45.8%) with 41.6% of them practicing as a family physician. Providers were asked some questions about the patients they see in their practice in general. Almost ¼ (25.2%) of these providers' patients have Medicare, 37.5% of their patients are current smokers and 35.1% of these patients are former smokers.

Table 2.2: Health Care Providers' Characteristics

| Table 2.2: Health Care Providers' Characteristics | |
|---|---------------------|
| A. Practice Characteristics | Count (%) |
| <i>Providers' practice Setting</i> | |
| Hospital system | 10 (40.0%) |
| Individual practice | 8 (32.0%) |
| Group practice | 5 (20.0%) |
| Community health center | 1 (4.0%) |
| Other | 1 (4.0%) |
| <i>Race/Ethnicity of the providers' patients</i> | |
| Non-Hispanic White | 23 (31.5%) |
| Black or African American | 23 (31.5%) |
| Hispanic | 23 (31.5%) |
| Other | 4 (5.4%) |
| <i>Insurance Coverage of the providers' patients</i> | |
| Medicare | 24 (25.2%) |
| Medicaid | 22 (23.1%) |
| Un-insured | 22 (23.1%) |
| Private insurance | 22 (23.1%) |
| Other | 5 (5.2%) |
| <i>Smoking history of the providers' patients</i> | |
| Current Smoker | 37.5% (of patients) |
| Former Smoker | 35.1% (of patients) |
| B. Demographic Information | Count (%) |
| <i>Health Care Providers' Gender</i> | |

| | |
|--|------------|
| Male | 12 (50.0%) |
| Female | 12 (50.0%) |
| Health Care Providers' Race/Ethnicity | |
| Non-Hispanic White | 22 (91.6%) |
| Black or African American | 0 (0.0%) |
| Hispanic | 0 (0.0%) |
| Other | 2 (8.3%) |
| Health Care Providers' Age | |
| 20-39 Y | 5 (20.8%) |
| 40-49 Y | 7 (29.1%) |
| 50-59 Y | 11 (45.8%) |
| 60-79 Y | 1 (4.1%) |
| Health Care Providers' Specialty | |
| Family medicine | 10 (41.6%) |
| Internal medicine | 6 (25.0%) |
| Oncologist | 2 (8.3%) |
| Pulmonologist | 1 (4.1%) |
| Radiologist | 0 (0.0%) |
| Other | 5 (20.8%) |

Table 12.2: Health Care Providers' Characteristics

Health care providers' knowledge & attitude about lung cancer screening

Health care providers answered 1) Yes, 2) No, and 3) Maybe to 9 statements to test their knowledge, attitude and beliefs toward lung cancer screening.

These statements are listed below:

| # | Statement |
|---|--|
| 9 | Even if the cost is an issue, I would still recommend low-dose CT screening to my patients at high risk for lung cancer. |
| 8 | If cost is Not an issue, I would recommend low-dose CT screening to my patients at high risk for lung cancer. |
| 7 | There is no need to educate patients about low-dose CT because in general they want to be screened. |
| 6 | The scientific evidence is strong enough to warrant a screening guideline for high-risk patients. |
| 5 | Low-dose CT creates enough anxiety to negate the value of screening. |
| 4 | The rate of false positives for low-dose CT is too high. |
| 3 | Low-dose CT screening for lung cancer is cost-effective. |
| 2 | There is clear evidence that low-dose CT for lung cancer screening saves lives. |
| 1 | The benefits of low dose CT outweigh the risk for patients at high risk for lung cancer. |

Providers' responses to these statements are shown in Figure 2.6.

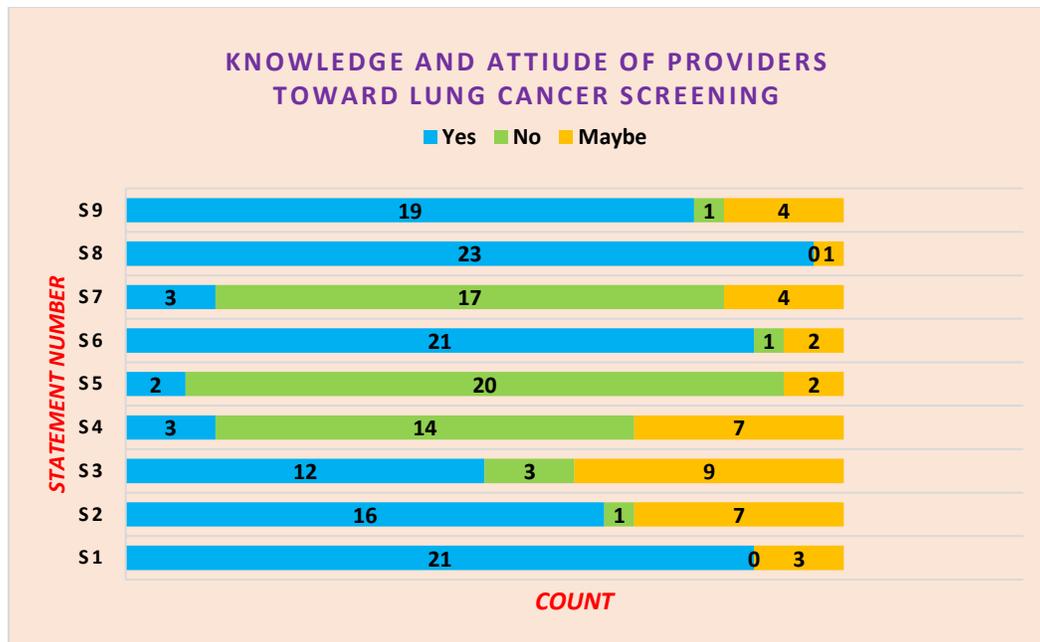


Figure 2.6: Knowledge & attitude of providers toward lung cancer screening

Below is the description and analysis of the providers' responses to the 9 statements:

- *Statement 1: “The benefits of low dose CT outweigh the risk for patients at high risk for lung cancer.”*

There are many studies in the literature that proved the benefits of LDCT outweighs the risks and that’s why this test became the gold standard for screening of lung cancer. Out of 24 providers, 21 agreed that this is the true statement.

- *Statement 2: “There is clear evidence that low-dose CT for lung cancer screening saves lives.”*

This Statement indicates that there is a clear evidence that Low-Dose CT saves lives.

Considering the literature review provided for this paper, LDCT is a gold standard for screening of lung cancer and the results of the NLST, has shown a 20% reduction in lung-cancer specific mortality with LDCT screening in a high-risk population.⁷⁷ Even though 16 providers (66.6%) think this is a true statement, 8 providers (33.3%) don’t think this is a true statement (No/Maybe).

- *Statement 3: “Low-dose CT screening for lung cancer is cost-effective.”*

Half of the providers (22) think this statement is true while the other half think it is not true or they are not sure.

- *Statement 4: “The rate of false positives for low-dose CT is too high.”*

Majority of the providers (14) think this is not true statement. In fact, since the false positive rates are not high, this test has become the best test for lung cancer screening.

- *Statement 5: “Low-dose CT creates enough anxiety to negate the value of screening.”*

It is true that some patients might experience anxiety during the test but benefit of finding lung cancer at early stages is very important (and could save lives) that the anxiety couldn’t be a

reason to avoid the test. For this statement *again*, most of the providers (20) think this is not true statement.

- *Statement 6: “The scientific evidence is strong enough to warrant a screening guideline for high-risk patients.”*

This statement is about the necessity of having a screening guideline for high risk populations, 21 providers (87.5%) responded that they agree with this statement, which in fact now the USPTSF and other organizations such as NCCN (National Comprehensive Cancer Network) have specific screening guidelines for high risk individuals.

- *Statement 7: “There is no need to educate patients about low-dose CT because in general they want to be screened.”*

Patients need to be educated on the importance of early diagnosis for improved lung cancer outcomes. This is more important among high risk smokers. Most the respondents (21) agree that patients need to be educated on this topic.

- *Statement 8: “If cost is Not an issue, I would recommend low-dose CT screening to my patients at high risk for lung cancer.”*

From 24 providers, 23 responded that if cost is not an issue they would recommend the screening (1, maybe).

- *Statement 9: “Even if the cost is an issue, I would still recommend low-dose CT screening to my patients at high risk for lung cancer.”*

From all the providers, 19 mentioned that they still recommend the screening. Cost is an important barrier to receiving the screening. However, comparing the responses of the providers

to the statement 8 & 9 shows that most providers believe the screening is very important that even if the cost is an issue, they would recommend the screening.

Results: Patients

The study was designed to recruit patients who had been referred for lung cancer screening (Low-Dose CT) at the Martinsville Henry County Memorial Hospital within the past 3 years (2015, 2016, 2017).

From 139 patients, 34 participated in the survey (1 online, 33 paper surveys) after the first mailing with a response rate of 24.4%. A second reminder invitation packet was sent out to 105 patients on February 12th, 2018 by the Hospital administration (excluding those who participated in the first round). In the second invitation, 14 patients participated (2 online). In total, 49 out of 139 invited patients participated in the study with a response rate of 35.2%. Participants in the study were asked to return the paper survey along with their contact information (to get the \$15 gift card) directly to the study team, or to access the survey online. Upon receiving the survey responses, the study team sent out the gift card along with the thank you note (appendix).

Patients' characteristics

Patients' characteristics are presented in table 2.3. Patients are mostly white (85.7%), female (61.2%), heavy smokers (average 41.1 years smoked in the past), low income (28.5% under \$15,999 annual income), and age 55-75 (83.6%).

| Table 2.3: Patients' Characteristics | |
|--|-------------|
| A. Smoking Information | Count (%) |
| Current smoker | |
| Yes | 31 (63.2%) |
| No | 18 (36.7%) |
| Frequency of smoking | |
| Current every day smoker | 30 (96.7%) |
| Current some day smoker | 1 (3.2%) |
| Smoking on a regular basis in the past | |
| Yes | 49 (100.0%) |
| No | 0 (0.0%) |
| Years smoked in the past | |
| 10 to 25 Y | 3 (6.1%) |
| 26 to 35 Y | 13 (26.5%) |
| 36 to 45 Y | 15 (30.6%) |
| 46 to 55 Y | 13 (26.5%) |
| 56 to 65 Y | 4 (8.1%) |
| 66 to 70 Y | 1 (2.0%) |
| Intensity of smoking | |
| >1 pack per week | 1 (2.0%) |
| 1-2 packs per week | 6 (12.2%) |
| 2-3 packs per week | 2 (4.0%) |
| 3-4 packs per week | 2 (4.0%) |
| 4-5 packs per week | 12 (24.4%) |
| 5 or >5 packs per week | 26 (53.0%) |
| B. Lung CT Screening History | Count (%) |
| Suspicious findings after lung CT screening | |

| | | |
|-----------------------------------|---------------------------|------------------|
| | Yes | 11 (22.9%) |
| | No | 37 (77.0%) |
| Screening compliance* | | |
| | Early complier | 32 (65.3%) |
| | Late complier | 13 (26.5%) |
| C. Demographic Information | | Count (%) |
| Gender | | |
| | Male | 19 (38.7%) |
| | Female | 30 (61.2%) |
| Race | | |
| | White | 42 (85.7%) |
| | Black or African American | 6 (12.2%) |
| | Asian | 1 (2.0%) |
| Age | | |
| | 18-39 Y | 0 (0.0%) |
| | 40-49 Y | 1 (2.0%) |
| | 50-54 Y | 1 (2.0%) |
| | 55-75 Y | 41 (83.6%) |
| | 75+ Y | 6 (12.2%) |
| Education | | |
| | Some high school | 8 (16.3%) |
| | High school graduate | 12 (24.4%) |
| | Some college credit | 14 (28.5%) |
| | Associate degree | 6 (12.2%) |
| | Bachelor's degree | 5 (10.2%) |
| | Master's degree | 4 (8.1%) |

| | | |
|---------------------------|------------------------|------------|
| Insurance Coverage | Medicare | 39 (50.0%) |
| | Medicaid | 8 (10.2%) |
| | Un-insured | 0 (0.0%) |
| | Private Insurance | 19 (24.3%) |
| | Other | 12 (15.3%) |
| Employment | Part time Employee | 1 (1.8%) |
| | Full time Employee | 10 (18.8%) |
| | Self-Employed | 2 (3.7%) |
| | Un-employed | 1 (1.8%) |
| | Retired | 30 (56.6%) |
| | Disable/Enable to work | 9 (16.9%) |
| Income | > \$15,999 | 14 (28.5%) |
| | \$16,000 to \$25,999 | 3 (6.1%) |
| | \$26,000 to \$40,999 | 12 (24.4%) |
| | \$41,000 to \$55,999 | 10 (20.4%) |
| | \$56,000 to \$75,999 | 4 (8.1%) |
| | \$76,000+ | 4 (8.1%) |

* Screening compliance has been defined as receiving a lung cancer screening within 8 weeks of the physician's recommendation.

Table 2.13: Patients' Characteristics

The US Preventive Services Task Force (USPSTF) recommends annual screening for lung cancer with low-dose computed tomography (LDCT) in adults aged 55 to 80 years who have a 30 pack-year smoking history and currently smoke or have quit within the past 15 years.⁸⁹ Most study participants are older than 55 years old (95.91%) and are heavy smokers. This is not a very

surprising finding as they have already received the test and being a heavy smoker is the eligibility criteria for most health insurers (such as Medicare) to cover the costs of the screening.

Figure 2.7 shows patients' smoking years:

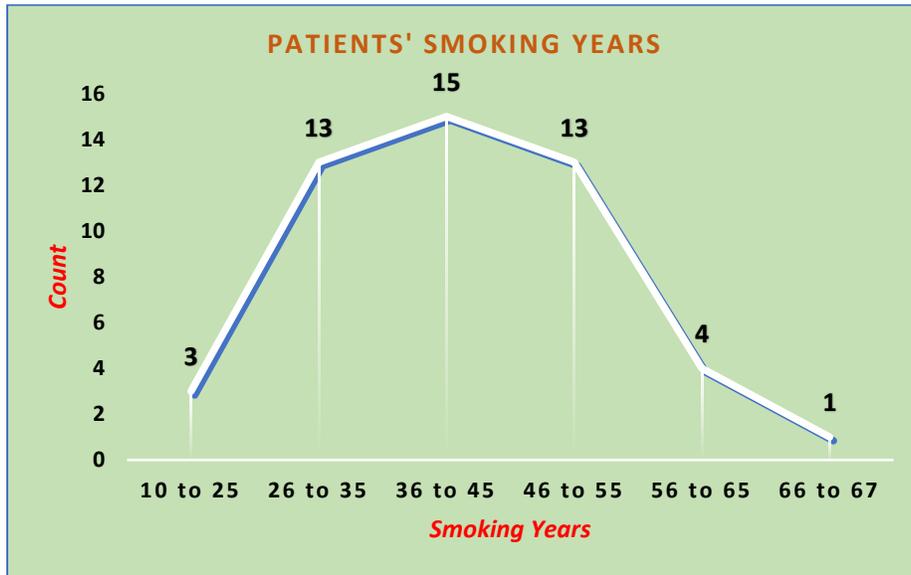


Figure 2.7: Smoking years of patients (count)

Patients' knowledge & attitude about lung cancer screening

Patients answered 15 short questions to test their knowledge, attitude and beliefs toward lung cancer screening. They chose from the three answer choices: 1) Yes, 2) No, and 3) Maybe. These questions are listed below:

| # | Questions |
|----|--|
| 15 | Were you nervous about getting the lung CT screening? |
| 14 | Do you think the price of the test is reasonable and affordable for most people? |
| 13 | Do you think lung CT screening is a reliable test for detecting the lung cancer? |
| 12 | Do you think getting lung CT screening is easy and convenient for most people? |
| 11 | Do you believe that early detection of lung cancer will lead to a better outcome of the disease? |
| 10 | Do you believe that smokers are at high risk for lung cancer? |

| | |
|---|--|
| 9 | Do you believe healthy eating and being active can decrease chances of getting lung cancer? |
| 8 | Were you scared of the lung CT screening itself? |
| 7 | Do you believe lung CT screening is an uncomfortable/painful procedure? |
| 6 | Do you believe a normal result from a lung CT screening means that smokers can continue to smoke without worrying? |
| 5 | Do you believe receiving a normal result from lung CT screening could decrease worry of developing lung cancer? |
| 4 | Do you believe a lung CT screening will decrease risk of dying from lung cancer? |
| 3 | Were you scared by thoughts of a lung cancer diagnosis when your doctor recommended the lung CT screening? |
| 2 | Do you believe CT radiation could cause lung cancer? |
| 1 | Were you worried about being diagnosed with lung cancer when your doctor recommended the lung CT screening? |

Patients responses to these 15 questions are presented in Figure 2.8.

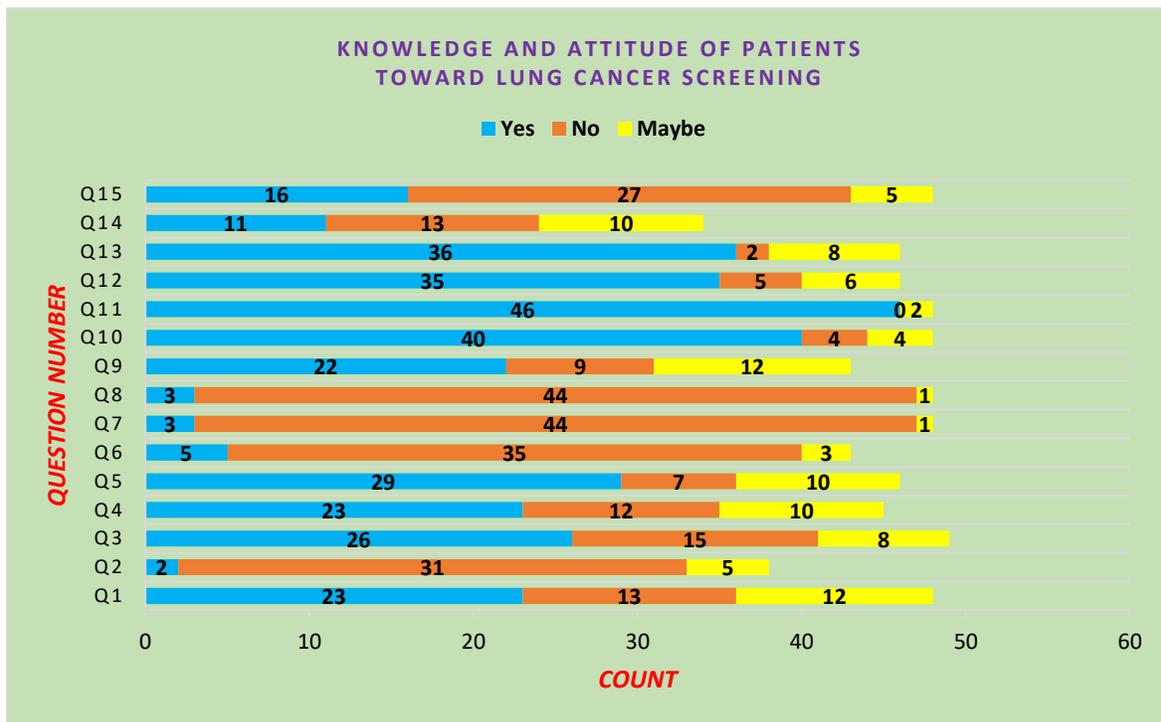


Figure 2.8: Knowledge & attitude of patients toward lung cancer screening

Below is the description and analysis of the patients' responses to these 15 questions:

- *Q1: Were you worried about being diagnosed with lung cancer when your doctor recommended the lung CT screening?*

From 48 patients who responded to this question, 23 said yes, 13 said No and 12 of them said maybe. Nearly half of the patients were worried about being diagnosed with lung cancer on that time.

- *Q2: Do you believe CT radiation could cause lung cancer?*

From 38 patients who responded to this question, only 2 of them think that CT radiation could cause lung cancer. Majority of the respondents (31) think CT radiation cannot cause lung cancer.

- *Q3: Were you scared by thoughts of a lung cancer diagnosis when your doctor recommended the lung CT screening?*

All patients (49) responded to this question. More than half of them (53%) were scared by thoughts of lung cancer diagnosis on that time.

- *Q4: Do you believe a lung CT screening will decrease risk of dying from lung cancer?*

From 45 patients who responded to this question, nearly half of them (23) believe that lung CT screening will decrease risk of dying from lung cancer.

- *Q5: Do you believe receiving a normal result from lung CT screening could decrease worry of developing lung cancer?*

From 46 patients who responded to this question, 29 (63%) believe that normal results could decrease worry of developing lung cancer.

- *Q6: Do you believe a normal result from a lung CT screening means that smokers can continue to smoke without worrying?*

Most of the respondents (81%) believe that having a normal lung CT screening result doesn't mean that smokers can continue smoking.

- *Q7: Do you believe lung CT screening is an uncomfortable/painful procedure?*

From 48 patients who responded to this question, 44 chose No. Still 3 patients believe the test is an uncomfortable and painful procedure.

- *Q8: Were you scared of the lung CT screening itself?*

The responses to this question is exactly as for Q7. From 48 patients, 3 of them were scared about the test itself.

- *Q9: Do you believe healthy eating and being active can decrease chances of getting lung cancer?*

One of the questions (Q9) is about the effect of lifestyle on lung cancer outcomes and is assessing patients' knowledge about *whether eating healthy and being active could decrease chances of getting lung cancer*. Around 51.16% of the respondents replied "Yes", 20.93% replied "No", and 27.9% mentioned "Maybe". There are many studies⁹⁰ that show the positive effect of healthy eating and being active on the lung cancer outcomes while only half of the patients believe this is important.

- *Q10: Do you believe that smokers are at high risk for lung cancer?*

From 48 respondents, 40 of them agree that smokers are at high risk of lung cancer while 4 patients think smokers are not at high risk and 4 of them are not sure.

- *Q11: Do you believe that early detection of lung cancer will lead to a better outcome of the disease?*

Early detection of the lung cancer is crucial to get better outcome for people who have lung cancer disease which 95.8% of the respondents believe this is true.

- *Q12: Do you think getting lung CT screening is easy and convenient for most people?*

From 46 patients who responded to this question, 35 think it's an easy and convenient test for most people. It is important to consider the fact that the target population for the patients' group in this study are the patients who already took the test. Therefore, they don't reflect the opinion of the patients who have been referred to get the screening who, because of some barriers, have not been able to get it.

- *Q13: Do you think lung CT screening is a reliable test for detecting the lung cancer?*

It has been discussed in the introduction section that LDCT currently is the gold standard test for lung cancer screening. From 46 patients who responded to this question, 35 of them (76%) think it's a reliable test.

- *Q14: Do you think the price of the test is reasonable and affordable for most people?*

Only 34 patients have responded to this question. Almost an equal number of patients chose yes, no and maybe (11,13,10).

- *Q15: Were you nervous about getting the lung CT screening?*

From 48 patients who responded to this question, more than half of them (27) were not nervous about getting lung CT screening.

Lung cancer screening facilitators among early complier patients

Screening compliance has been defined as receiving a lung cancer screening within 8 weeks of the doctor's recommendation. In the patients' survey, participants first were asked when they got

their screening and then they were asked if they received the screening within 8 weeks of the doctor’s recommendation or later than 8 weeks. By answering yes or no patients are divided into 2 groups; early compliers and late compliers.

In the early complier’s group, patients were directed to choose from a list of the facilitators that helped them to get the screening in a timely manner. These facilitators are the most common screening facilitators found in the literature. There is also an “other” option to allow patients (early compliers) to write if they had a different facilitator not listed in the question. Table 2.4 shows these facilitators.

| Table 2.4: Common screening facilitators | |
|---|--|
| Facilitator ID | Screening Facilitator |
| F1 | I had an insurance that covered cost of the screening |
| F2 | I had a family member with lung cancer and was worried I might also have lung cancer |
| F3 | My physician explained why I needed to get the screening on time |
| F4 | I was a smoker and wanted to make sure I don't have lung cancer |
| F5 | My family convinced me to get the screening on time and not to postpone it |
| F6 | Other |

Table 2.14: Common screening facilitators

The results of the responses from early compliers to the question on what has helped them to get the screening on time is available in Figure 2.9.

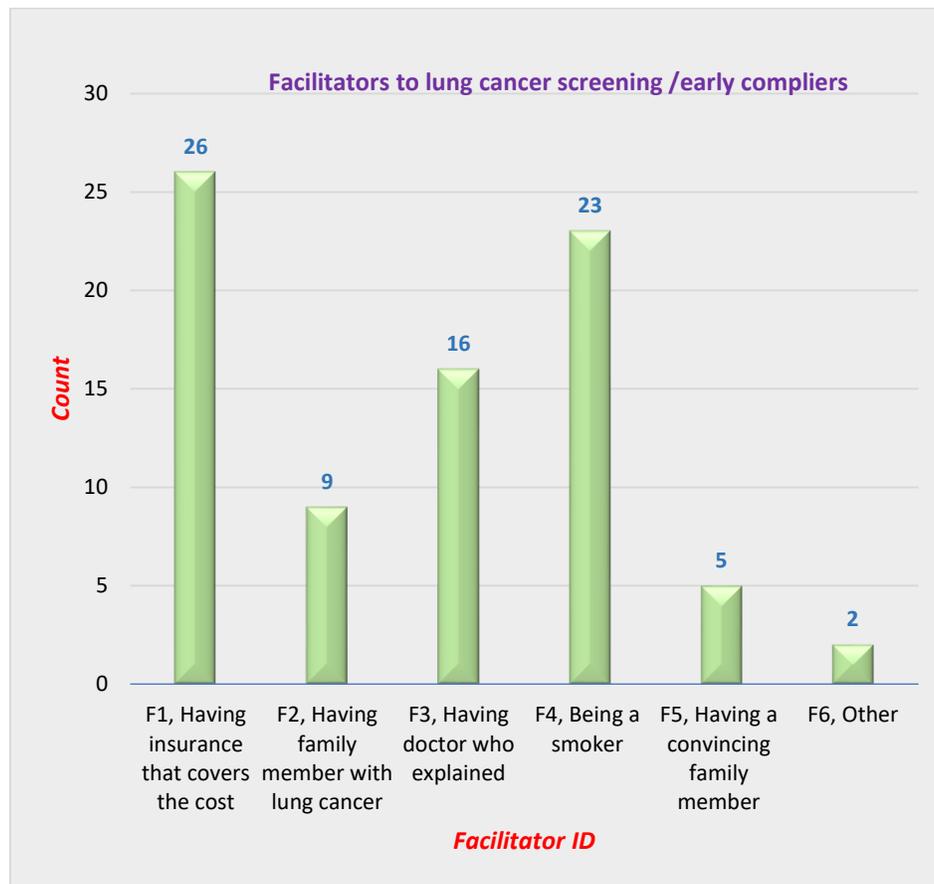


Figure 2.9: Screening Facilitators among early compliers

Figure 9 shows that F1 (*I had an insurance that covered cost of the screening*) is the most important factor in helping early compliers get the screening on time and after that, is F4 (*I was a smoker and wanted to make sure I don't have lung cancer*).

This finding is in line with the results already presented in the patients' knowledge and attitude section in Figure 8. In the set of the questions to test their knowledge and attitude toward lung cancer screening, Q5 has asked the patients "*Do you believe receiving a normal result from lung CT screening could decrease worry of developing lung cancer?*" Most patients (#29) answered "Yes" to this question (10 answered: No and 7 answered: Maybe).

In other words, we can conclude that since most of the patients who participated in the study were smokers, they decided to get the screening to make sure they don't have lung cancer (F4) because they believed receiving a normal result from lung CT screening could decrease worry of developing lung cancer (answer to Q5 in the knowledge section). After F4, F3 was the most important barrier. (*My physician explained why I needed to get the screening on time*).

Other facilitators:

The least important facilitator was F6 (other). Two patients wrote in the comment section that the cost of the screening was covered by "AARP", and the doctor ordered the test due to other types of cancer.

Lung cancer screening barriers among late complier patients

In the late compliers' group, they are asked to determine which of the barriers to lung cancer screening (Ten most common screening barriers, See Table 1) is a major barrier, minor barrier or not a barrier for them. The results are in Figure 2.10.

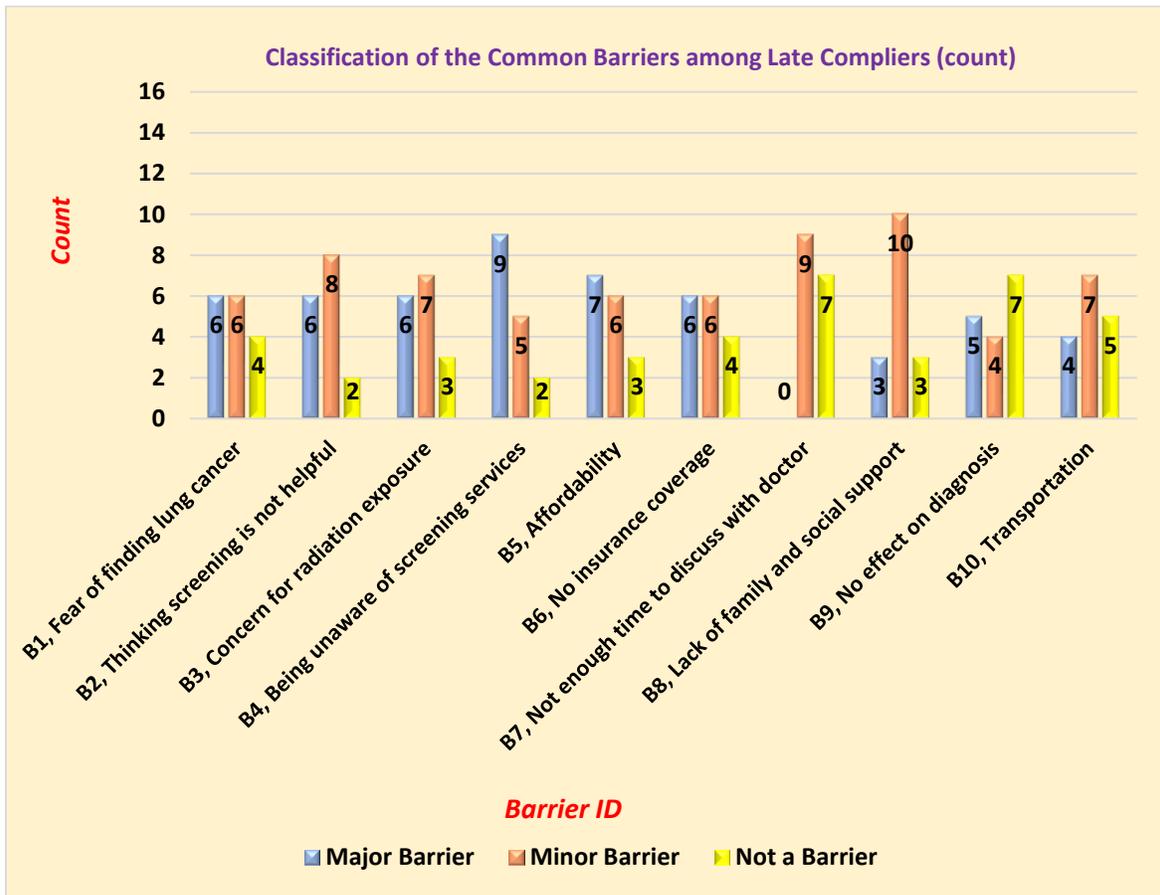


Figure 2.10: Classification of the common barriers among late compliers (count)

The concept of “major”, “minor”, and “not a barrier” was defined as the patients’ simple ranking based on their first impression when they read the list of the barriers. All patients ranked the list of the common barriers (in scale of 1 to 10) at the beginning of the survey and late compliers ranked the same list of the barriers as major, minor or not a barrier again. The goal of repeating the ranking for late compliers is to find out which barrier is the most important barrier for late compliers.

Based on the information on Figure 10, B4 (*People are unaware of lung cancer screening services*) is a major barrier for most of the late compliers, B8 (*People don’t have family and social support to help them get the screening*) is a minor barrier for most of the late compliers and B7 (*There is not enough time to discuss lung cancer screening with physicians*) & B9 (*People think timely screening, will not have effect on diagnosis or disease outcome*) are not a barrier for most of the late compliers.

Moreover, B1 & B2 & B3 are major barriers for the same number of patients (6/6/6) while these barriers are minor barriers for the almost the same number of the patients (6/8/7). We can also look at these results in a different way.

The number of patients who viewed B4 & B2 as a barrier (major/minor) is 14. For B8, 10 patients have viewed this barrier as “minor” and 3 as “major” (total: 13) and this total number for B3 is also 13. From these numbers we can conclude that B4 & B2 are more important for later compliers than B8 & B3 while B4 is more important than B2 (more patients said B4 is a major barrier). We can conclude that B4 is the most important barrier for late compliers.

Other barriers:

There was a question to explore whether patients (late compliers) had any other barrier than the 10 listed barriers. Some of the other barriers were 1) insurance denied the test, 2) having extreme pain, 3) making the appointment at the time that allows the person to keep it was hard.

Comparison of the responses from early compliers & late compliers

The most important facilitator among early compliers is F1 *“I had an insurance that covered cost of the screening”*. This is consistent with the late compliers as the majority of the later compliers (12 out of 16 that responded to this question) identified that as a barrier. Therefore, we can conclude that having insurance coverage is a very important factor in determining patients’ decision to get the screening. Another facilitator among early compliers that could be compared to barriers among late compliers is F3 *“My physician explained why I needed to get the screening on time”* which could be compared to B7; *“There is not enough time to discuss lung cancer screening with physicians”* among late compliers. This is an interesting finding that *“lack of spending enough time between physicians and providers”* is an important barrier that if addressed properly could help patients in becoming early compliers.

The least important facilitator among early compliers is F5 (*having convincing family member to get the screening*) which could be compared to B8 (*lack of family and social support*) among late compliers which has been identified as a minor barrier. We will later discuss that B8 is the most important barrier for both providers and patients. This could be explained by the fact that to become an early complier, having insurance coverage and a doctor to convince them to get the screening on time is more important than having a family member to convince getting the screening. Moreover, B8 (*People don’t have family and social support to help them get the screening*) is a minor barrier for most of the late compliers.

Comparison: Health care providers & patients' view of lung cancer screening barriers

Health care providers and patients had a common question in their surveys asking them to rank each of the 10 barriers in order of the importance from 1 to 10, with number 1 being the MOST important barrier and number 10 being the LEAST important barrier. Mean of the ranking for each barrier and standard deviation (SD) for each group is calculated using R software. Figure 2.11 presents mean of the ranking for each barrier among health care providers and patients. The mean of the ranking has the minimum of 3.5 and maximum of 8.1.

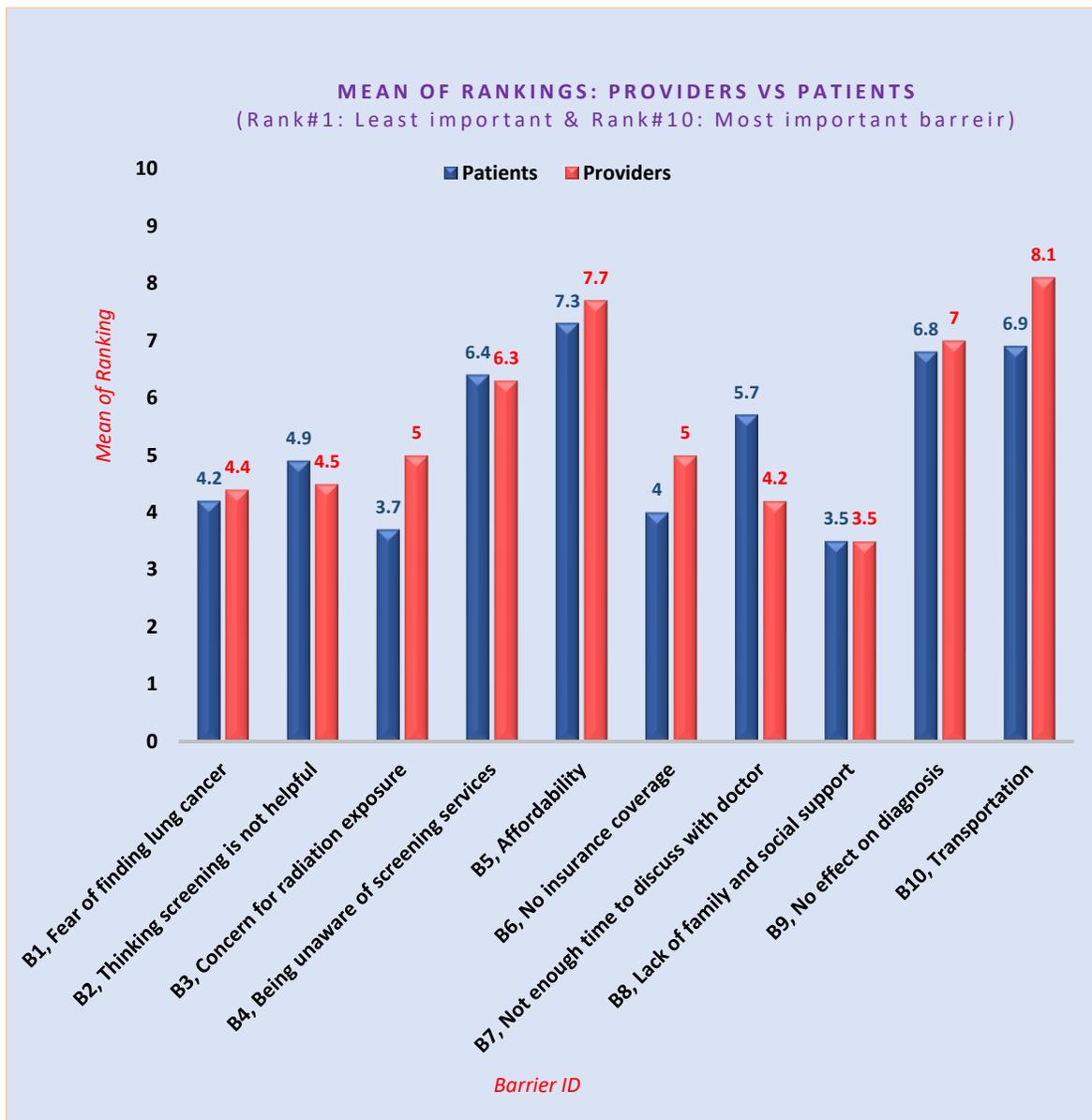


Figure 2.11: Comparison of mean of rankings: Health care providers VS Patients

Note: Rank #1 is the least important barrier and Rank # 10 is the most important barrier

Table 2.5 presents the means of the ranking and their standard deviations for each barrier among health care providers and patients.

| Table 2.5: Mean of ranking for barriers (& standard deviation) health care providers vs patients | | |
|---|-----------------------|----------------|
| Barrier ID | Health care providers | Patients |
| B1 | 4.4 (SD: 2.51) | 4.2 (SD: 3.27) |
| B2 | 4.5 (SD: 2.11) | 4.9 (SD: 2.36) |
| B3 | 5 (SD: 3.14) | 3.7 (SD: 2.37) |
| B4 | 6.3 (SD: 2.85) | 6.4 (SD: 2.74) |
| B5 | 7.7 (SD: 2.20) | 7.3 (SD: 2.50) |
| B6 | 5 (SD: 2.12) | 4 (SD: 2.94) |
| B7 | 4.2 (SD: 2.55) | 5.7 (SD: 2.39) |
| B8 | 3.5 (SD: 2.18) | 3.5 (SD: 2.52) |
| B9 | 7 (SD: 2.19) | 6.8 (SD: 1.96) |
| B10 | 8.1 (SD: 2.44) | 6.9 (SD: 2.87) |

Table 2.15: Mean of ranking for barriers (&SD); health care providers VS patients

By looking at Table 2.5 and Figure 2.11 we observe that the most important barrier for health care providers & patients is B8 (*People don't have family and social support to help them get the screening*) with 3.5 as the mean ranking. The least important barrier for health care providers is B10 (*transportation*) with mean ranking of 8.1 and the least important barrier for patients is B5 (*People cannot afford the cost of lung cancer screening*) with mean ranking of 7.3. Table 2.6 shows the order of importance for each barrier among health care providers and patients.

| Table 2.6: Order of the importance of screening barriers: health care providers vs patients | | |
|--|-----------------------|----------|
| Order of Importance | Health care providers | Patients |
| 1 (Most Important) | B8 | B8 |
| 2 | B7 | B3 |
| 3 | B1 | B6 |
| 4 | B2 | B1 |
| 5 | B3 & B6 | B2 |
| 6 | | B7 |
| 7 | B4 | B4 |
| 8 | B9 | B9 |
| 9 | B5 | B10 |
| 10 (Least Important) | B10 | B5 |

Table 2.16: Order of the importance / screening barriers

Order of importance of the barriers between health care providers and patients is shown in Table 6. The most important barrier for both providers and patients is B8 (*lack of family and social support*). The second most important barrier for health care providers is B7 (*There is not enough time to discuss lung cancer screening with physicians*) while the second most important barrier for patients is B3 (*Peoples' concern for radiation exposure*).

Some barriers such as B3 & B7 are more important for one group but less important for the other group. By looking closer at the information, B7 is the second most important barrier (order # 2) for health care providers but is less important for the patients (order # 6). This could be explained because patients in this study have received the screening recommendation from their physicians

and therefore, might have already spent enough time to discuss the screening with their providers to decide to get the screening.

Another barrier is B3 that is the second most important for patients while it is the fifth important (order # 5) for providers. This could be explained by providers increased medical knowledge that low-dose CT doesn't cause any radiation harm and its benefits are greater than the risks.

Most other barriers are within one position in ranking from each other (B1, B2, B5, B10) or they have the exact same ranking order (B4, B8, B9).

2.5 DISCUSSION

This study explores the lung cancer screening barriers from the perspective of the health care providers and patients and at the same time examines the screening barriers among late compliers and screening facilitators among early compliers. To our knowledge this is the first study designed to explore the lung cancer screening and facilitators among two groups at the same time.

In evaluation of the responses to test the knowledge and attitude of the patients, it is important to consider the participant characteristics and the fact that target population for the patients' group in this study are patients who already received the screening. For instance, evaluation of the patients' responses to Q12 (Figure 8) shows that from 46 patients who responded to this question, 35 think it's an easy and convenient test for most people. Their answers don't reflect the opinion of the patients who have been referred to get the screening but have not been able to get it.

Classification of the common barriers among late compliers have been presented in Figure 2.10. By referring to this Figure, B4 (*People are unaware of lung cancer screening services*) is a major barrier for most of the late compliers, B8 (*People don't have family and social support to help them get the screening*) is a minor barrier for most of the late compliers. The information on Figure 2.10 (late compliers) and Table 2.5 (patients' section) could be compared. This comparison reveals that what is important for all the patients combined might be different when considering only late compliers.

The main finding of this comparison is that B8 is the most important barrier for all patients while B4 is the most important barrier for patients who are late compliers. The main reason that late compliers couldn't get their screening on time is they were un-aware of the lung cancer screening services (B4), which explains the main findings.

Another interesting finding in this comparison is that B4, while it is the most important barrier for late compliers, ranked # 7 among all patients. This could be explained by the higher percentage of early compliers compared to late compliers in this study (32/13, refer to table 3, patients' characteristics). In other words, clear communication between health care providers and patients in explaining available options for lung cancer services could result in improved compliance from patients.

The importance of effective communication between health care providers and patients is highlighted when comparing the responses of the early and late compliers (facilitators and barriers). Late compliers rank B7 "*lack of spending enough time between physicians and providers*" as a "minor" barriers while among early compliers spending time with the physician in explaining the screening is a facilitator (F3).

B7 was ranked #6 from all the patients (early and late compliers combined), as shown in Table 6. It is interesting that “*lack of spending enough time between physicians and providers*” is an important topic that needs to be the focus of future research because when health care providers spend enough time communicating the benefits of this screening and emphasize the importance of early detection with their patients, they are more likely to get the screening on time and become “early compliers”. But when this time is not spent with the patients, they are more likely to postpone getting the screening (or unfortunately not getting it at all) and become “late compliers”.

Most of the patients that participated in the study were white, high risk smoker, and low-income individuals who live in a medically underserved area. However, none of the participants are uninsured and they have Medicare, Medicaid or some other type of insurance. This background information about participants helps to understand some of the major findings of the study. Cost has been recognized as one of the major barriers to cancer screening in the scientific literature especially among low SES populations.^{61,91} However, “cost” as a screening barrier (B5) has been identified as the least important barrier for patients in this study while *lack of social and family support* (B8) is the most important barrier for them (from perspective of the providers and patients).

Patients’ responses to the questions that test their knowledge and attitude about lung cancer reveals that most of them have information about this screening and overall positive attitudes toward it. This could be because these patients have been provided some type of education at the time of receiving the screening.

Evaluation of the providers' responses to the statements that test their knowledge and attitude about lung cancer screening, shows that the majority of them have enough knowledge about lung cancer screening. This could be because Martinsville hospital started an initiative to promote lung cancer screening on November 2016 and most providers in the area have joined this initiative and are actively screening and referring patients to get LDCT for lung cancer screening.

Another point to consider is the importance of having an insurance that covers the cost of screening. Even though none of the participants in this study are un-insured, insurance coverage of the procedure could still be a barrier in specific situations. As an example, one of the participants in the study wrote a note on the survey that he was recommended to get the screening twice (in 2016 & 2017) but his insurance declined to cover the cost for the second time and he had to pay for the expense out of his pocket even though LDCT is an effective test to screen for lung cancer and should be offered annually. Therefore, insurance rules and complexities could be an additional burden for the patients even if they have some type of insurance that claims to cover the cost of the screening.

2.6 LIMITATIONS

Memorial Hospital of Martinsville didn't obtain email addresses from the patients who received the LDCT in the past 3 years. Therefore, recruiting participants was limited to distributing the paper surveys. We tried to overcome this limitation by including the survey link in the hospital invitation letter that was sent out to the patients as well as providing e-mail of the study team for them to request the survey link if they preferred. Another limitation was that most patients who participated in this study are high risk individuals with low socio-economic status who live in

underserved areas and therefore the results of this study might not be generalizable to the general population of the United States. It is also important to recognize that the patients in this study all had some form of insurance (none of them were uninsured). Therefore, the results of the study might not be generalizable to the general population that some patients may not have any insurance coverage.

Another limitation is that by asking health care providers and patients about the lung cancer screening, we rely on their reporting, and thus, responses are subject to recall bias.

There is a lack on scientific literature to compare the knowledge, attitude and barriers of health care providers toward lung cancer screening with the patients. To our knowledge, this study is the first to capture this research gap and therefore, the design of this study and the surveys might contain some limitations. However, we are hoping the results of this study and lessons learned will provide valuable suggestions for further research in exploring this research gap.

2.7 CONCLUSIONS

There are many studies that have been conducted to explore the lung cancer screening barriers. Some of these studies are directed to the patients and some to the health care providers. To our knowledge, this is the first study that aims to compare the screening facilitators and barriers among patients to promote the lung cancer screening and is the first study to explore screening barriers and knowledge and attitudes toward this screening from the perspective of the patients and providers. Based on the comparison of the results of the providers and patients (explained in the discussion) we conclude that the relations/communication between providers and patients in receiving the cancer screening could be studied more in detail in the future studies.

Results of the study show that these two groups have similar as well as distinct perceptions of the main barriers to lung cancer screening. They both view “*lack of social and family support*” as the most important barrier to lung cancer screening but there are some differences on how they view other barriers. Identifying these differences enables health care providers, policy makers and public health professionals to focus on addressing the most important barriers to each population group; providers and patients. They can also learn from those who had positive experiences (such as early compliers) to implement the screening facilitators into their educational programs or consider them in policy making decisions. This statement is true about the findings of this study about screening facilitators among early compliers and the screening barriers in the late complier patients. This is more important in communities with limited resources that need to prioritize actions to improve lung cancer screening referral and compliance.

2.8 FUTURE RESEARCH & DIRECTION

The development of decision aids may facilitate shared decision-making discussions about screening, and targeted interventions may improve knowledge gaps.⁸⁵ Educational opportunities for health care providers should address current barriers, including financial cost, insurance coverage, data on frequency of false positive results, and complications arising from screening to provide primary care physicians with the knowledge needed to have shared decision-making conversations about lung cancer screening with their patients.⁸⁶

Future research is needed into models of care with structured, lung cancer risk assessment, surveillance of compliance and psychosocial support to improve screening recommendation and compliance. Also, research into the effectiveness of lung cancer screening algorithms in assessing individual lung cancer risk in the U.S. population such as Qcancer which have been

designed and are being used in the UK have the potential to increase awareness and increase patient's compliance with screening.⁹² There is also a need for studies to address the practical barriers related to access, with behavioral interventions designed to minimize emotional barriers, especially among current smokers.⁸³

Some studies have shown that designing programs to normalize the attitude toward screening could have impact on the acceptance of lung cancer screening by recipients especially among smokers.⁸⁴ These programs should aim to normalize the screening program in a way that smokers don't feel singled out. Designing smoking cessation advice after the screening is regarded as appropriate if delivered sensitively. For population-based implementation of lung cancer screening, physicians and trainees will need resources and time to address the benefits and harms with their patients.⁷³ Physicians can be trained to achieve and maintain patient-centered communication skills.⁸⁷

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CHAPTER 3:

Conclusion

The first chapter of this dissertation focused on analyzing the three conceptual models developed by the stakeholder engagement method. The process of selecting diverse groups of stakeholders for the design of the models led to a broader range of knowledge which enriched the final product of the prioritized research agenda. Therefore, including diverse stakeholders in this method could potentially improve the process of research translation to address health issues of relevance for the communities. The second chapter of this dissertation reports on the lung cancer screening project which was designed based on the research gap identified as result of conceptual models (SEED project) and the prioritized research agenda previously conducted in that community. This study assessed the knowledge and attitudes of health care providers and patients toward low dose CT and explored the barriers as well as facilitators to lung cancer screening from the perspective of the health care providers, early complier patients, and late complier patients.

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APPENDICES

A. Appendices for Analysis of the Concept Models

1.1 Matrix 1 and 2 Facilitation Guide to Choose TOPIC groups

Matrix 1: Patient Stakeholder Identification Facilitation Guide

Purpose: This matrix will be used to identify patient stakeholder participants by demographic, social, and other health related criteria, to participate as a TOPIC group member in this project

What you will need:

- Matrix 1: Patient Stakeholder Identification (projected)
- Demographics information handout
- Information from Informational Interviews
- Rank cards (one set per Research Team member)

Instructions and Facilitation Questions:

Introduction:

“There are many ways in which patients and caregivers impacted by lung disease can be involved in this project. There are three different participant groups, and each type of participation has a different role.

TOPIC groups: This is the most involved group of stakeholders we will be working with throughout the project. They will be involved in a total of 7 meetings and will talk at length about their experience with lung cancer. Each TOPIC group will develop a conceptual model diagramming the factors that influence lung cancer outcomes based on their own experience and will create research questions that are important to them. It’s important to remember that each TOPIC group will bring their own unique perspective of the health topic to the table, and both their conceptual models and research questions will reflect this unique perspective and experience. Therefore, we want to consider who would be the best people to serve in this role throughout the project.

Today we will work through an activity to help us determine who we’d like to be a part of the TOPIC groups in this project. Other ways patients, caregivers, and providers can be involved in this project include:

Focus groups: Focus groups are interactive group meetings that allow participants to share their experiences, perceptions, and opinions about our health topic (lung cancer). People involved in this type of participant group will be involved in a one-time only, 90-minute focus group. We will have a total of 6 different groups, which will allow us to recruit many people we’re interested in talking to and learning from. This is also a great way for people to participate who may not be able to commit to a more involved,

long-term commitment like the TOPIC groups. The TOPIC groups we pick will be the ones to decide who they'd like to be a part of the Focus Groups.

Key informant interviews: Approximately 12 different one-on-one interviews will be done with this type of participant and will last between 30 and 60 minutes. These interviews can be done over the phone or face-to-face at any time during the day or evening, based on the interviewees' schedule. This allows us to include people in our study that might not be able to meet for longer periods of times (TOPIC groups) or are not able to attend a focus group. Rather, this allows us to include people who have busy schedules and who we may not be able to engage beyond a 60-minute phone interview or who might prefer to meet privately (i.e., health care providers (MDs), policymakers, etc.). TOPIC Groups will also choose who should be a Key Informant Interview."

Step 1: Choosing patient sub-groups:

Purpose: This step is meant to help the research team brainstorm different patient sub-groups affected by the health topic. There is flexibility in choosing which patient categories and subgroups to use (far left-hand side of the matrix) – add/delete categories as necessary. Begin this brainstorm without looking at or projecting the matrix. Facilitator should write down all patient groups on a board or flip-chart. After completing brainstorming, edit the categories in the matrix before projecting.

FQ 1: Who is affected by lung cancer? (without looking at matrix – facilitator writes list on board)

- *What did we discover about who is affected by lung cancer from the demographics information handout?*
- *In our informational interviews, what were some of the local organizations and resources we learned about? What people/patients do they serve? Do they target any specific groups of people?*
- *Which patients in this community are at high risk? Are there certain people at risk because of the type of work they do? Because of age, gender, behavior, other medical conditions, etc?*
- *Which patients in this community have trouble accessing care or services?*
- *Which patients in this community might provide a unique perspective?*

After completing brainstorming, edit the categories in the matrix.

Step 2: Choosing decision criteria:

Purpose: To help reduce the size of the initial brainstormed list of patient subgroups, the research team will decide upon which groups of patients should be prioritized and included as patient participants in TOPIC groups. This will be accomplished

by having them decide upon a set of decision criteria. These criteria will be used to rate each patient subgroup and should be filled in across the top (columns) of Matrix 1.

FQ1: How should we decide which groups of patients we want to include as part of our patient TOPIC groups?

- ***What are some decision criteria we should use?***
 - ***Is prevalence of this disease (how common it is) in a particular group important?***
 - ***Is the presence of this group in our community important?***
 - ***Should we specifically prioritize vulnerable groups of people?***
 - ***What about a groups risk level – risk of complications, death, poor health outcomes?***
 - ***Other decision criteria?***

Have the group vote on the top 3 criteria they want to use

Step 3: Ranking each patient subgroup according to criteria:

Purpose: Rank each patient subgroup according to the decision criteria decided on in the last step. Each person will get a set of rank cards (Low, Medium, High) to use for ranking each patient subgroup on the various criteria. The project coordinator will count the number of votes for each ranking and use the ranking with the most votes. The project coordinator should convert this ranking to the following number system:

Low = 1 point
Medium = 2 points
High = 3 points

Step 4: Weight responses, prioritization of patient subgroup and Final Decision:

Purpose: For each patient subgroup, the research coordinator should add up all the criteria rankings for a total score. Place this number in the 'Decision' column. (Can create an equation within excel to automatically populate this score.) The subgroups with scores of 8 points or more* will be carried over to the next step as prioritized patient subgroups for TOPIC groups. Highlight all groups that were carried-over in yellow.

*This number can be adjusted and reduced if this eliminates too many patient subgroups

MOVE ONTO MATRIX 2: SERVICE PROVIDER/OTHER STAKEHOLDER IDENTIFICATION

Matrix 2: Service Provider/Other Stakeholder Identification Facilitation Guide

Purpose: This matrix will be used to identify all Health Care, Service provider and Policymaker stakeholders to participate as TOPIC group members.

What you will need:

- Matrix 2: Service Provider/ other Stakeholder Identification (projected)
- Information from Informational Interviews
- Rank cards (one set per Research Team member)

Step 1: Choosing Service Provider/Other Stakeholder sub-groups:

Purpose: This step is meant to help the research team brainstorm different service provider sub-groups involved with the health topic. There is flexibility in choosing which categories and subgroups to use (far left-hand side of the matrix) – add/delete categories as necessary. Begin this brainstorm without looking at the matrix. Facilitator should write down all patient groups on a board or flip-chart. After completing brainstorming, edit the categories in the matrix before projecting.

FQ 1: Who is involved with lung cancer? (without looking at matrix – facilitator writes list on board)

- *In our informational interviews, what were some of the local organizations and resources we learned about? What types of professionals are serving in these organizations?*
- *What types of health care professionals serve people with lung cancer?*
 - *What types of service providers are important for people with lung cancer? (e.g., social services, health education, etc.)*
- *What other types of professionals may work in the area of lung cancer? (research, policy, insurance, advocacy)*
- *What other type of stakeholder might bring a unique and important perspective about lung cancer?*

After completing brainstorming, edit the categories in the matrix.

Step 2: Choosing decision criteria:

Purpose: To help reduce the size of the initial brainstormed list of service providers/other stakeholders, the research team will decide upon which groups of stakeholders should be prioritized and included as participants (either as TOPIC group members, Focus Group participants, or Key Informant Interviews). This will be accomplished by having them decide upon a set of decision criteria. These criteria will be

used to rate each patient subgroup and should be filled in across the top (columns) of Matrix 1.

FQ1: How should we decide which groups of service providers/other stakeholders we want to include in this project? (TOPIC groups, Focus groups, and Key Informant Interviews)

- ***What are some decision criteria we should use?***
 - ***Is the amount or type of professional experience, expertise, and knowledge important to consider?***
 - ***What about how much contact they have with patients with lung cancer?***
 - ***Ability to affect the services that patients receive?***
 - ***Ability to affect the policy environment?***
 - ***A unique perspective on lung cancer outcomes?***
 - ***Anything else?***

Step 3: Ranking each service provider subgroup according to criteria:

Purpose: Rank each service provider/other stakeholder subgroup according to the decision criteria decided on in the last step. Each person will get a set of rank cards (Low, Medium, High) to use for ranking each patient subgroup on the various criteria. The project coordinator will count the number of votes for each ranking and use the ranking with the most votes. The project coordinator should convert this ranking to the following number system:

Low = 1 point
Medium = 2 points
High = 3 points

Step 4: Weight responses, prioritization of service provider subgroup and Final Decision:

Purpose: For each service provider/other stakeholder subgroup, the research coordinator should add up all the criteria rankings for a total score. Place this number in the 'Decision' column. (Can create an equation within excel to automatically populate this score.) The subgroups with scores of 8 points or more* will be carried over to the next step as prioritized patient subgroups for TOPIC groups. Highlight all groups that were carried-over in yellow.

*This number can be adjusted and reduced if this eliminates too many patient subgroups

NEXT WEEK: CHOOSING COMPOSITION OF TOPIC GROUPS

Choosing composition of TOPIC Groups

What you'll need:

- Flip chart
- Sticky notes or index cards (voting)

Step 1: Choosing composition of TOPIC groups:

Purpose: As part of this study, the research team is limited to having a total of three different stakeholder TOPIC groups – at least 1 of which must be service providers. Therefore, they can have up to 2 groups be patient groups of their choosing.

****Throughout this process, the Research Coordinator/Group Facilitator should coach the group to not go so narrow that it makes finding participants difficult, but also not to rule out groups because of issues such as age, literacy, or how busy they are (e.g., MDs) ****

Step 1a: Brainstorming Patient Stakeholder TOPIC Groups:

[On a piece of paper (or projected), list out all the highlighted prioritized patient subgroups from Matrix 1.]

FQ1: Looking at our final list of patient subgroups (those that were retained with the highest scores), who should we include as participants in our TOPIC groups? It's important to understand that each group of people will bring a unique perspective to this project that will be reflected in their conceptual models and research questions. This may be helpful in thinking about who we want to include in these patient groups, as well as the feasibility of engaging them throughout the project.

- ***Does it make sense to include any of these groups together?***
- ***What 'criteria' would you like participants to meet to be eligible for the group? (i.e. Must be an African American over 65 years of age?)***

FQ2: Why is it important to include these groups?

FQ3: What information are we wanting to learn from them? What unique perspective would they provide? What might we expect to hear from them?

FQ4: How feasible would these groups be to recruit for and retain throughout the 7 TOPIC group meetings?

Step 1b: Voting on Patient Stakeholder TOPIC Groups:

1. Each member of the research team should propose a specific TOPIC group composition of their choosing. Go around the circle and write down each TOPIC group that is suggested.
2. Prior to voting, the research coordinator/facilitator should work to combine and eliminate redundancies and overlaps among the brainstormed list of TOPIC groups.

3. To narrow down groups, each research team member should be given ballots to cast their vote (stickies). The number of ballots each person receives should be equal to 1/3 of the number of TOPIC groups listed.
4. Research team members should vote on their top TOPIC groups.
5. Repeat this voting process (if necessary) until there are only 2 patient TOPIC groups remaining. These will be the two-prioritized patient stakeholder TOPIC groups.

Step 1c: Brainstorming Service Provider Stakeholder TOPIC Group:

[On a piece of paper (or projected), list out all the highlighted prioritized provider/other stakeholder subgroups from Matrix 2.]

FQ1: Looking at our final list of provider subgroups (those that were retained with the highest scores), who should we include as participants in our TOPIC groups? It's important to understand that each group of people will bring a unique perspective to this project that will be reflected in their conceptual models and research questions. This may be helpful in thinking about who we want to include in this TOPIC group, as well as the feasibility of engaging them throughout the project.

- ***Does it make sense to include any of these groups together?***
- ***What criteria would you like participants to meet in order to be eligible for the group? (i.e. Must be an African American over 65 years of age?)***

FQ2: Why is it important to include these groups?

FQ3: What information are we wanting to learn from them? What unique perspective would they provide? What might we expect to hear from them?

FQ4: How feasible would these groups be to recruit for and retain throughout the 7 TOPIC group meetings?

Step 1d: Voting on Service Provider Stakeholder TOPIC Group:

1. Each member of the research team should propose a specific TOPIC group composition of their choosing. Go around the circle and write down each TOPIC group that is suggested.
2. Prior to voting, the research coordinator/facilitator should work to combine and eliminate redundancies and overlaps among the brainstormed list of TOPIC groups.
3. In order to narrow down groups, each research team member should be given ballots to cast their vote (stickies). The number of ballots each person receives should be equal to 1/3 of the number of TOPIC groups listed.
4. Research team members should vote on their top TOPIC groups.
5. Repeat this voting process (if necessary) until there is only 1 TOPIC group remaining. This will be the prioritized provider stakeholder TOPIC group.

NEXT WEEK: DECIDING WHERE TO RECRUIT TOPIC GROUP PARTICIPANTS FROM

Part I: Path Diagram Training (40 minutes) – Meeting #4

Prepare: <https://www.youtube.com/watch?v=2O0gudOnayo>

Facilitator 20-40 [Facilitator draws on white board or other large area to illustrate examples.]
minutes

Supplies needed for this training activity:

- White board
- Large Sticky notes
- Dry Erase Markers

Step 1: Introduction to path diagrams:

Today we are going to be learning how to develop diagrams called ‘conceptual models’ or ‘path diagrams’. These diagrams are pictures we can use to help us organize information and show cause and effect relationships.

Step 2: Developing a path diagram using ‘Car’ example:

Let’s say we are interested in predicting whether someone will buy a new car. We’ll call ‘buying a car’ the OUTCOME. Let’s draw a circle at the right and label it ‘buy car’

[On white board, write ‘Buy a car’ on the far-RIGHT side.]

Buy a car

We use a process called a ‘path diagram’ to map out relationships. We are going to map out the reasons people generally make decisions, or generally do something, such as buy a car. We understand that there are always exceptions to any rule, but today we want to focus on these ideas generally.

Step 2a: Brainstorming factors:

What are some important reasons someone might buy or not buy a car? *[Facilitator or group member should write each reason on a large sticky note and place on the far-LEFT side of board.]*

Probe for the following variables:

- Savings/credit
- Condition of old car
- Commuting
- New baby

Probing questions:

- What else influences whether someone will buy a car?
- Why might someone choose to buy a car?
- Who might be in the market to buy a new car?

[**The example conceptual model on the last page does not include all the possible factors that predict buying a car. Please adjust as needed and be sure to include the factors your group brainstorms during this step.**]

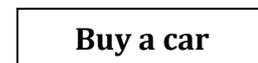
Step 2b: Developing first path:

Let's think a little more about savings/credit... does anything important affect whether someone has good savings/credit to buy a car?

Probe for:

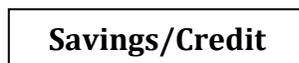
- *Employment or income*

Let's call Income a PREDICTOR, because it helps predict the OUTCOME ('buy a car') and put it all the way on the left side of the model. [Place 'income' on left side of board.] Now if income usually causes someone to have better savings/credit, we can draw an arrow from 'income' to 'savings/credit'. [Draw one-way arrow from 'income' to 'savings/credit'.] The one-way arrow means that it has some type of impact on where the arrow points. So, we call 'Income' a PREDICTOR and 'savings/credit' a MEDIATOR, because it mediates or comes between the relationship 'income' and 'buying a car'. This arrow only means probability, not a rule.



(Example of exception – probe for recognition of exception. Can you have a good income and bad credit/no savings? Yes. Can you have low income and good credit/good savings? Yes. However, in most cases you will see that as income rises, credit and savings rise too. Now let's draw an arrow from 'savings/credit' to 'buy a car'. [Draw one-way arrow from 'savings/credit' to 'buy a car'.] Again, this arrow means probability not a certainty. Can you have good credit and savings, yet still not buy the car? Yes, but chances are, the better your credit and income, the higher the probability that you will buy the car.)

We now have one path in our diagram.



Step 2c: Incorporating other factors into path diagram:

Now the diagram becomes more complicated. Let's think more about each of the other factors we brainstormed. What about condition of old car? Does something important come first, meaning, what predicts the condition of your old car? [Facilitator or group member should write each factor on a sticky note and place in diagram.]

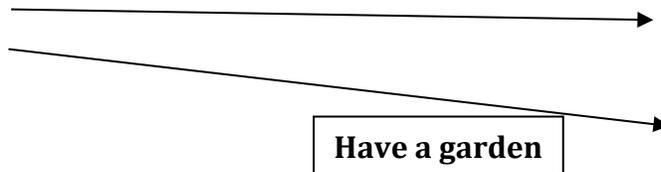
- *Probe for income/employment*

What about commuting? Does anything important come first? Is everyone equally likely to commute?

- *Probe for age, rural/urban*
- *Probe for bidirectional relationships like income and age* – How does age affect a person's income?

When there is no relationship we leave an arrow out. If 'commuting' and 'savings/credit' are not related to each other, meaning one doesn't cause a change in the other, then we don't need an arrow there.

Sometimes we find that variables look related to the outcome we are interested in, but they are really not important at all. Here is an example: a gardening club finds data that people with gardens were more likely to buy cars than people without gardens. Does having a garden cause people to buy cars? Probably not. Another explanation is that people in rural and suburban areas are more likely to have gardens and are also more likely to buy cars. Where you live (rural, suburban, urban) causes both items to change, but there is no real relationship between having a garden and buying a car. That is called **CONFOUNDING**. It looks like there is a relationship because both items tend to change (more gardens = more car buying), but that is only because both items are affected by the same thing (where you live).



Step 3: Review the model

Review all of the paths in the model. Do they make sense? Are the arrows in the right place? Is anything important missing?

Step 4: Using model to predict who will buy a car:

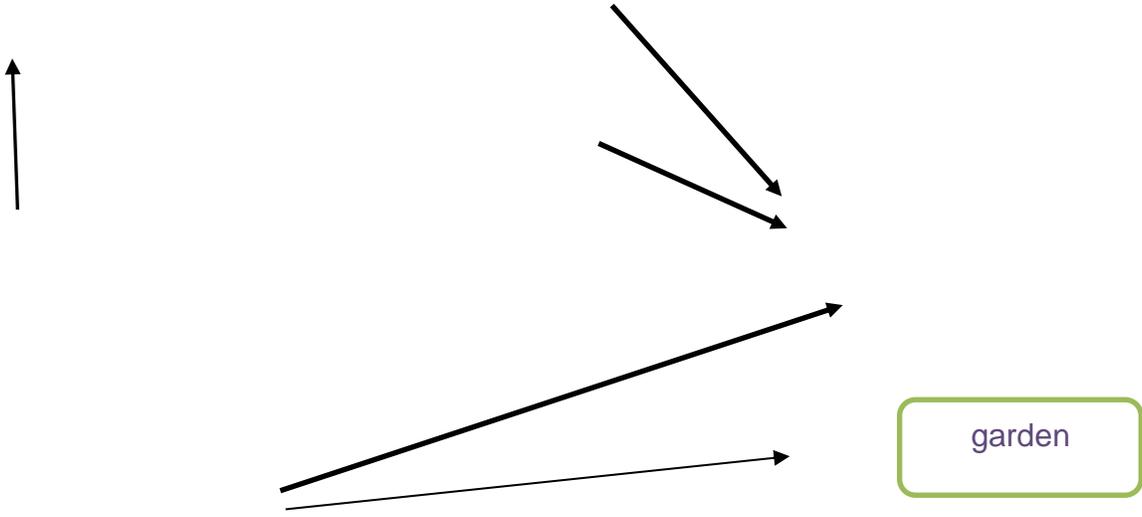
Now we have a path diagram. We can use it to make predictions about who would be most likely to buy a car. We can gather data on who buys cars and test which of the paths in the model are strongest (or the most likely to happen), and maybe find that some don't matter very much after all.

Facilitation questions:

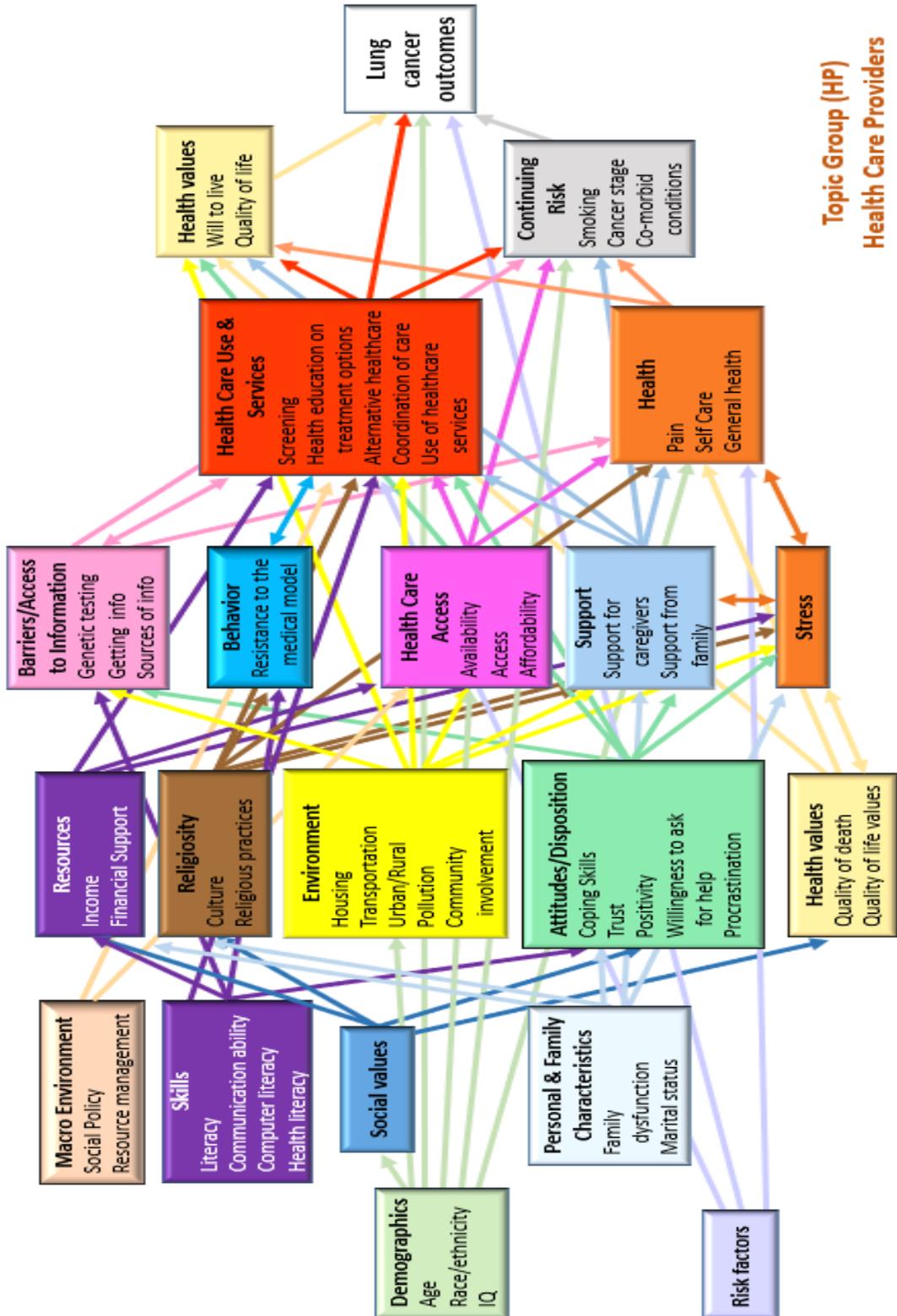
- What do you think makes this model useful?
- If you were selling cars, how would this model affect who you will try to sell a car to? How about where you build a car dealership?
- If you were selling cars, would this model help you? Why?
- If you were buying a car, would this model help you? Why or why not?

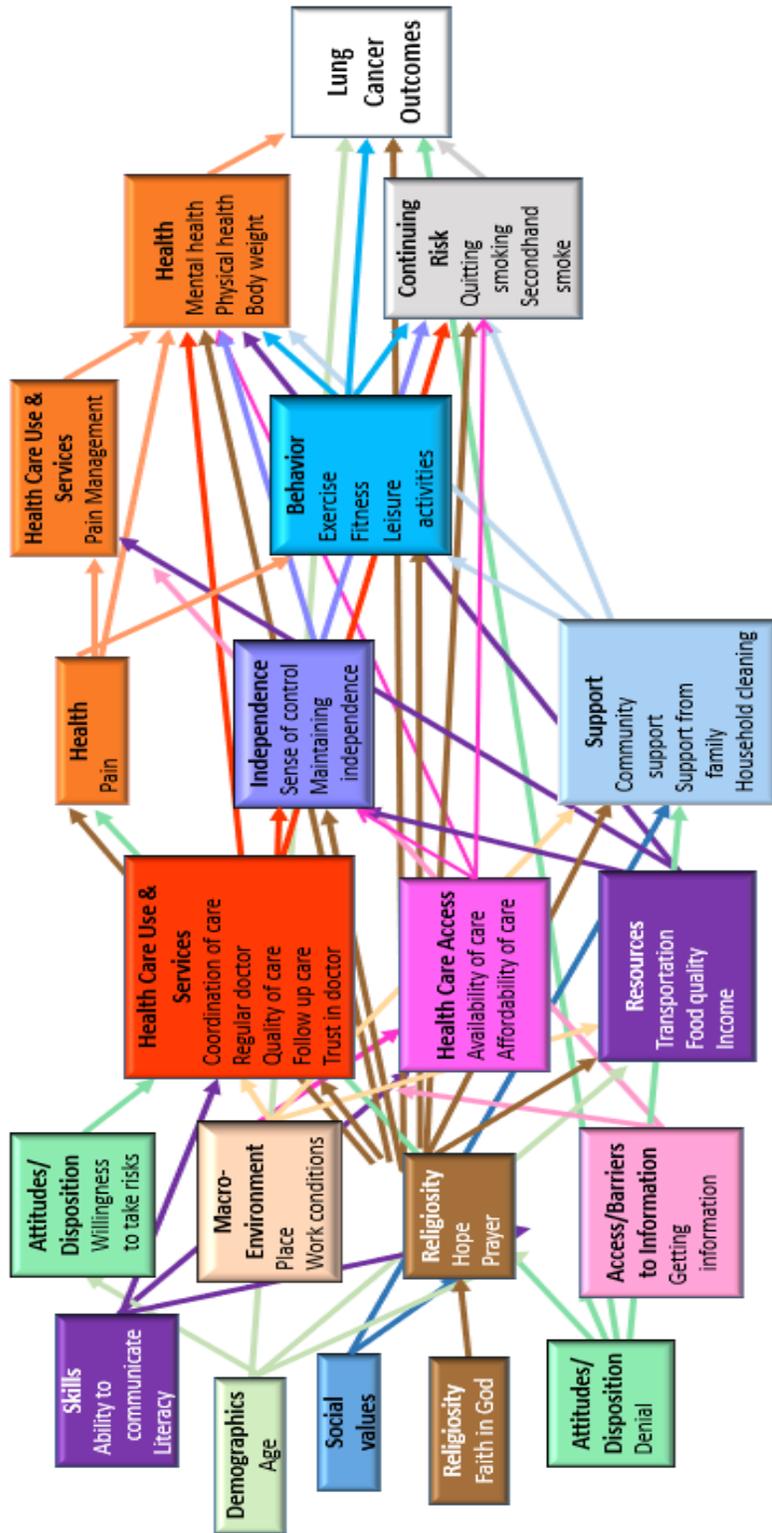
| | |
|-----------------------------|---|
| Facilitator | Pass out or display sample path diagram. |
| Facilitator and TOPIC group | Discuss path diagram and answer questions |

Sample Path Diagram for Training

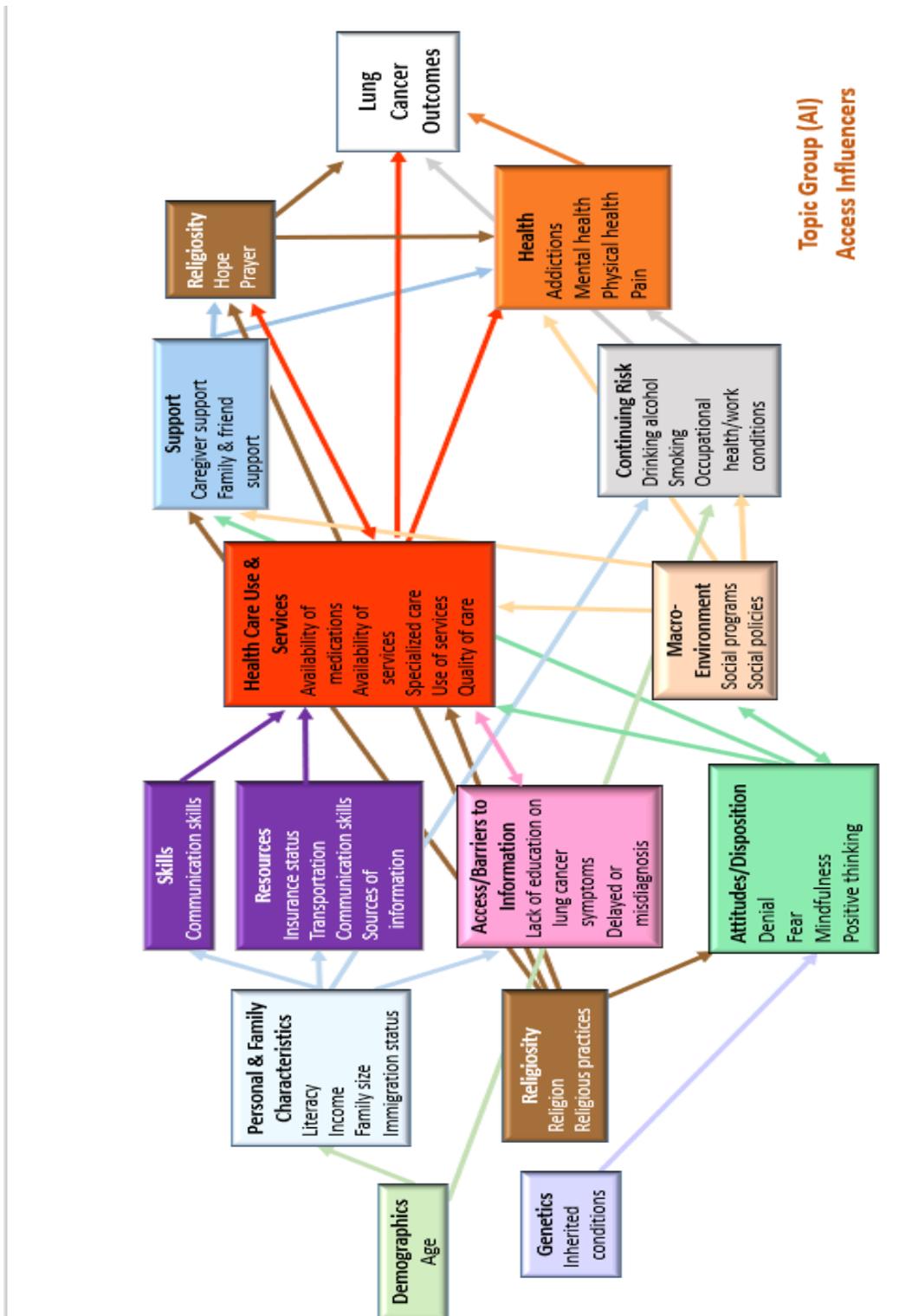


1.3 Final Conceptual models developed by 3 topic groups





Topic Group (SC)
Survivors & Caregivers



Topic Group (A1)
Access Influencers

B. Appendices for Lung Cancer Screening Project

2.1 SEED Method Brochure

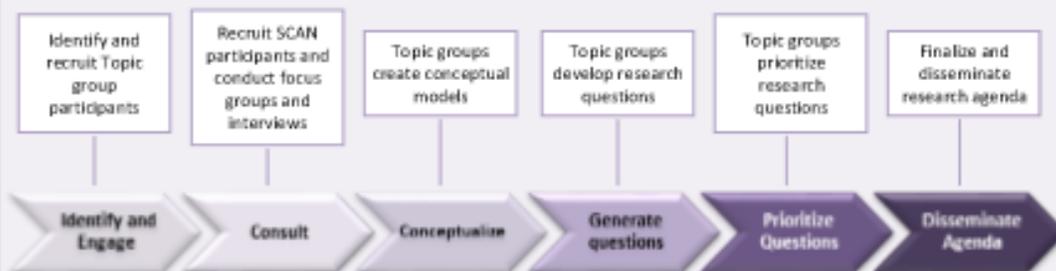


What is the SEED Method and how can it be used?

The Stakeholder Engagement in quEstion Development and prioritization (SEED) Method is a stakeholder engagement methodology that combines participatory modeling and question development with a review of available evidence. The SEED Method uses a multilevel stakeholder engagement model that is led within a participatory framework to develop stakeholder priorities, such as research topics or questions. Engagement encompasses three levels of participation:

1. A community-based participatory **Research Team** that collaboratively leads the project from beginning to end
2. Participatory **Topic Groups** of stakeholders brought together based on their experience and knowledge of the health-related topic that develop research questions
3. Consultative stakeholder participation through focus groups and interviews (**SCAN** participants)

The SEED Method was designed to take place in six steps over the course of nine months, however the method was designed to be flexible and scalable to fit with alternative timelines and objectives.



Although specifically created for the development of research questions, we encourage users to consider alternative uses of the method, such as identifying research priorities or intervention ideas, or developing participatory models as part of planning process for research projects.

Who can use the SEED Method?

- Researchers
- Organizations – including community-based and health systems
- Decision-makers
- Project teams – including coalitions

Those who wish to plan stakeholder-engaged research, involving people in multiple levels of participation, and who seek to create research priorities or agendas around a health topic would benefit the most from using the SEED method.

 Center on Society and Health

Customizable tools for:

- Engaging in participatory research
- Creating conceptual models diagramming causal pathways
- Developing stakeholder-generated priorities
- Using the scientific literature to refine research questions and priorities



SEED Method evaluation findings from two demonstration projects

- The SEED Method resulted in **unique conceptual models and research questions** across diverse stakeholder groups
- The final research agendas were understandable, informative, and impactful – with external stakeholders noting research questions were of interest to them/their organization and that agendas make an important contribution to research in the field
- The SEED Method process enhanced community and stakeholder capacity, including **personal growth, skill development**, and increase in **knowledge and skills** of participants
- Participants report high satisfaction with their participation in the SEED Method

What are participants saying about the SEED Method?

"I had never did anything like [this project], I've done things similar but not to this extent where my voice actually mattered and my opinions and what I said was taken in consideration..." - Research Team participant

"The process of developing research that's really relevant to the kind of challenges that people are having is so important...research in general is far off base compared to what I learned from patients..." - Research Team participant

"[I liked] the group interaction, in terms of how we all assisted each other in clarifying our questions for the exercise given." - Topic group participant

What does the toolkit provide?

An overview of the SEED Method, instructions, example documents – including timelines, meeting agendas, and powerpoint slides – and customizable templates – including organizational documents, facilitation guides, and training materials. An optional evaluation module is also included as part of the toolkit for users who would like to assess SEED Method processes or outcomes.

Who developed the toolkit?

The SEED Method was funded through a Patient-Centered Outcomes Research Institute (PCORI) Award (#1310-07664) to Emily Zimmerman (Principal Investigator), Center on Society and Health at Virginia Commonwealth University.

The toolkit was developed by members of the SEED method team - Emily Zimmerman and Sarah Cook.

Where can I can get the toolkit?

All materials are free and available for download at: go.vcu.edu/SEED

Need additional information about the toolkit or SEED Method? Contact us at:

VCU Center on Society and Health
One Capitol Square
830 E. Main Street, Suite 5035
P.O. Box 980212
Richmond, VA 23298-0212

Emily Zimmerman, PhD
emily.zimmerman@vcuhealth.org

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Martinsville Prioritized Research Agenda

Topic Group 1 – Lung Cancer Survivors & Caregivers

1. Why is there no help available through the healthcare system to discuss alternative treatments, natural choices, diet and nutrition?
2. If society required insurance companies to offer free annual checkups with x-rays would lung cancer be diagnosed earlier?
3. What are the factors of patient's faith (for example, knowing what happens when you die, feeling of peace or seeing family members again) and knowing family and community are praying for them; how does this affect lung cancer outcomes? Does it reduce stress, and does it change your outlook?
4. Does living in a poverty-stricken area vs an area of higher standards affect lung cancer?

Topic Group 2 – Health Care Providers

5. If patients knew more about hospice goals and palliative care, would it affect treatment decisions & outcomes?
6. If we could affect perceptions of care at local hospitals (MHMC) & providers, would it change outcomes?
7. Would more assistance navigating the healthcare system improve outcomes?
8. If we could improve general health of the population would it affect lung cancer outcomes?

Topic Group 3 – Access Influencers

9. If screenings and early detection occur does MHC (local hospitals) have the resources and technology to provide efficient and expedited methods to diagnose and stage?
10. If healthcare insurance coverage was standardized for diagnosis and treatment of cancer, would lung cancer outcomes become better?
11. Would paid FMLA (Family Medical Leave Act) legislation for caregivers benefit lung cancer outcomes and how?
12. If the Primary Care Physician recommended regular screening, they meet qualifying guidelines, and the cost was covered, would they have screenings? What are the reasons why not? Would it change the lung cancer outcomes?

2.3 Hospital Invitation Letter to Patients



December 16, 2017

Dear Patient,

Our hospital records show that you have visited SOVAH Health in the past 5 years. We are contacting you on behalf of Fatemeh Zarghami, a student at Virginia Tech University in the Department of Human Nutrition, Foods and Exercise. She is working as a research assistant with Dr. Carlin Rafie, Assistant Professor. Dr. Rafie's research team, in collaboration with SOVAH Health, is conducting a study to engage community stakeholders in the evaluation of different methods of improving lung cancer outcomes in Martinsville/Henry County.

Fatemeh is evaluating the knowledge and attitudes of patients and physicians regarding lung cancer screening, and barriers that prevent patients from getting screened after their physicians' recommendation. We believe the results of the project could provide valuable information about barriers to low dose screening CT. This project is part of Fatemeh's Ph.D. dissertation and the findings will be published as a dissertation within Virginia Tech University. Secondly, the information you provide will assist us, SOVAH Health, with minimizing barriers for future patients who need low dose screening CT scans.

This letter is coming directly from SOVAH Health, and your home address, nor your personal information has been released. The only information that Fatemeh will be provided is the information you provide for the \$15.00 gift card. Fatemeh is inviting you to participate in this study which is completely voluntary and confidential and all information from the survey is deidentified. You can participate in this study by either answering an online survey (with a separate link at the end to collect your mailing address for the gift card) which takes about 10 to 15 minutes to complete. The survey link is:

https://virginiatech.qualtrics.com/jfe/form/SV_bsy8wNEoz4xcl9z

OR if you prefer you may complete the enclosed paper copy and return it in the provided self-addressed envelop. Participants in the survey will be mailed a \$15 gift card as compensation of their time upon completion of the survey if the release document is provided with the address.

If you have 1) trouble accessing the online survey 2) have any questions about the study, 3) would prefer the survey be conducted on the phone, please contact Fatemeh at (fatemehz@vt.edu) with the subject line "*Martinsville Lung Cancer Screening Project*".

Thank you in advance for your time and willingness to help in this important study.

Sincerely,
Hospital Administration

P. O. Box 4788 * Martinsville, Virginia

(276) 666-7608

www.SovahHealth.com



MARTINSVILLE LUNG CANCER SCREENING PROJECT

To receive the \$15 gift card in appreciation of your time, please provide your contact information below. Please attach the finished survey, the gift card document and simply drop it in the post office mailbox:

First name/Last name:

.....

Mailing Address:

.....

.....

.....

Your contact information will be used only to send the gift card and the answers you provided in the survey will NOT be linked to your personal information.

If you have any questions, please contact Fatemeh Zarghami at:

E-mail: fatemehz@vt.edu

THANK YOU SO MUCH FOR BEING PART OF THIS IMPORTANT STUDY.

2.5 Patients' Thank You Letter



MARTINSVILLE LUNG CANCER SCREENING PROJECT

Dear Participant:

I would like to sincerely thank you for your time to participate in the Martinsville lung cancer survey. Your input is valuable, and the results of this project will help to discover more information about barriers to lung cancer screening in Martinsville/Henry county area.

The enclosed \$15 Wal-Mart gift card is for appreciation of your time and willingness to be part of this important study.

Sincerely,

Fatemeh Zarghami, M.D., M.P.H
Ph.D. Candidate, Behavioral Science
Department of Population Health Sciences &
Department of Human Nutrition, Foods, and Exercise (HNFE)
(0430) 338 Wallace Hall, Virginia Tech

E-mail: fatemehz@vt.edu

2.6 IRB Approval Letter



Office of Research Compliance
Institutional Review Board
North End Center, Suite 4120, Virginia Tech
300 Turner Street NW
Blacksburg, Virginia 24061
540/231-4606 Fax 540/231-0959
email irb@vt.edu
website <http://www.irb.vt.edu>

MEMORANDUM

DATE: September 29, 2017 

TO: Carlin Rafie, Fatemeh Zarghami

FROM: Virginia Tech Institutional Review Board (FWA00000572, expires January 29, 2021)

PROTOCOL TITLE: Assessment of Knowledge, Attitude, and Beliefs toward Low-Dose Computational Tomography (LDCT) Screening for Lung cancer and existing barriers among patients&physicians in Martinsville / Henry County; Virginia

IRB NUMBER: 17-550

Effective September 29, 2017, the Virginia Tech Institution Review Board (IRB) Chair, David M Moore, approved the New Application request for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report within 5 business days to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at: <http://www.irb.vt.edu/pages/responsibilities.htm>

(Please review responsibilities before the commencement of your research.)

PROTOCOL INFORMATION:

Approved As: **Expedited, under 45 CFR 46.110 category(ies) 5,6,7**
Protocol Approval Date: **September 29, 2017**
Protocol Expiration Date: **September 28, 2018**
Continuing Review Due Date*: **September 14, 2018**

*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

FEDERALLY FUNDED RESEARCH REQUIREMENTS:

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals/work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee.

The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.

Invent the Future

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY
An equal opportunity, affirmative action institution

| Date* | OSP Number | Sponsor | Grant Comparison Conducted? |
|-------|------------|---------|-----------------------------|
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* Date this proposal number was compared, assessed as not requiring comparison, or comparison information was revised.

If this IRB protocol is to cover any other grant proposals, please contact the IRB office (irbadmin@vt.edu) immediately.

2.7 Authors' Permission E-mail to Use Their Surveys

Kathryn E. Weaver <keweaver@wakehealth.edu>

11/21
/16

to me

Apologies for the delay. Attached is the questionnaire. If you use it in any way, please cite the paper you reference below. Thanks, KW

From: Fatemeh Zarghami [mailto:fatemehz@vt.edu]

Sent: Wednesday, November 16, 2016 8:55 AM

To: Kathryn E. Weaver

Subject: Re: Reminder - Request for Questionnaire of your Lung Cancer Screening study

EBERTH, JAN <JMEBERTH@mailbox.sc.edu>

11/28
/16

to KAREN, me

Fatemeh,

Delighted to hear of your interest in our work! I am happy to share a copy of our original survey in paper form with you. We have received some additional funding from the American Cancer Society to revise the survey and implement a national survey this year, which we are in the data collection process right now. I'd be interested to hear about the results of whatever work your team is doing on the topic of LDCT screening - it's near and dear to my heart. Always interested in building collaborations as well with like-minded researchers ☺

Again, thanks for your interest in our survey. Happy to provide you with the questionnaire that was used in the SC-only cohort (see attached).

Sincerely,

Jan M. Eberth

From: Fatemeh Zarghami [fatemehz@vt.edu]

Sent: Wednesday, November 23, 2016 5:34 PM

To: EBERTH, JAN

Subject: Request for Questionnaire of your Lung Cancer Screening Study (University of South Carolina)

If you would like to have a copy of the surveys, please contact Fatemeh Zarghami at:
fatemehz@vt.edu